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An Investigation of Dementia Screening Tools in a Cohort  
with Down syndrome and Intellectual Disability



Laura Williams  
Doctorate in Clinical Psychology

The University of Edinburgh  
September 2015

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Finally, to Matty and Ella. Thank you for always keeping me grounded in our everyday. This is for you.

Laura Williams

September 2015

## 1. THESIS ABSTRACT

**Objectives:** The following thesis is presented within two separate pieces of work. A systematic literature review (SLR) aimed to evaluate the individual characteristics and psychometric properties of four dementia screening tools. These were the Dementia Questionnaire for People with Learning Disabilities (DLD) (Evenhuis, 2007), the Dementia Scale for Down Syndrome (DSDS) (Gedye, 1995), the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb et al, 2007a) and the Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher et al, 2004). The empirical research (ER) aimed to evaluate the clinical utility and longitudinal accuracy of two of these tools; the DLD and the ABDQ in a clinical population with intellectual disability (ID) and Down syndrome (DS).

**Methods:** For the SLR a comprehensive list of electronic academic databases were searched to identify studies which included information relating to the psychometric properties of the DLD, DSDS, DSQIID and the ABDQ. Information within the studies was then extracted and rated using two quality assessment measures. These were the Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disabilities (CAPS-IDD) (Zeilinger et al, 2013b) and the Qualsyst (Kmet, 2004). For the ER, a repeated measures MANOVA was used to assess change over time between two groups of people with intellectual disabilities and Down syndrome; one with dementia and one without.

**Results:** In the SLR, 16 studies were identified and rated using the CAPS-IDD and the Qualsyst. Detailed information related to the dementia screening tools and quality ratings of the papers are provided.

In the ER both the ABDQ and the DLD demonstrated a clear difference between those who develop dementia and those who do not, with those in the 'dementia' group exhibiting increasing scores over time.

**Conclusions:** The SLR concludes that the evidence base for these dementia screening tools remain limited. The largest evidence base was evidenced for the DLD.

The ER concludes that the ABDQ and the DLD are useful tools to differentiate between those who develop dementia and those who do not. Further analysis incorporating the exploration of individual component items of tools is recommended.

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## THESIS PREFACE AND STRUCTURE

This thesis is about the psychometric properties and utility of tools and questionnaires used to screen and diagnose dementia in people with a learning disability. The thesis is presented in a portfolio format. The first section comprises a systematic review that focuses on the content of psychometric tools and measures used to screen for dementia in this population. The second is a piece of empirical research which investigates the use of specific tools, the Dementia Questionnaire for people with Intellectual Disabilities (DLD) and the Adaptive Behaviour Dementia Questionnaire (ABDQ). The empirical research uses longitudinal data from a clinical sample of people with intellectual disability and Down Syndrome.

Both sections follow the publication guidelines for The *Journal of Applied Research in Intellectual Disabilities* (JARID). In addition, The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA Group, 2009) was used to inform the methods employed in writing the systematic review. A list of references is included for each separate section immediately after the main body of the text for each. The guidelines for publication in The Journal of Applied Research in Intellectual Disabilities are included in the thesis appendices.

# **A Systematic Review of the Characteristics and Psychometric Properties of Four Assessment Tools for Dementia Screening in People with Intellectual Disabilities**

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## **Abstract**

**Background:** There are a number of assessment tools available to support the process of diagnosing dementia in individuals with intellectual disability (ID). This review aimed to evaluate the characteristics and psychometric properties of four assessment tools that are recommended in clinical practice for this purpose.

**Methods:** A systematic literature search across five databases (CINAHL, PsycInfo, Medline, Scopus and Web of Science) was conducted. Relevant studies were identified and selected using defined inclusion/exclusion criteria. 26 full-text articles were hand-searched. After selection, 16 studies were rated using the Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Disabilities (CAPS-IDD) (Zeilinger et al., 2013b). The CAPS-IDD provided a structured method of summarising the psychometric properties and conceptual and measurement information regarding the dementia screening tools.

Additionally, the individual papers were rated using the Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Qualsyst). A proportion of papers were rated independently by two researchers, as were two of the screening tools.

**Results:** In total, 104 studies were identified from initial search criteria. After excluding duplicates, screening titles and abstracts, a total of 26 studies remained and these were retrieved in full-text. Of these, 16 papers met the criteria for inclusion. The review highlighted a limited literature base for all screening tools, other than the DLD. The quality of the papers used to evidence them were also limited in quality.

**Conclusions:** The review demonstrates the evidence base for the four dementia screening tools remains limited. The DLD has the largest evidence base. Further validation studies would allow for greater understanding of the psychometric properties and accuracy of the tools.

**Keywords:** Dementia, Intellectual disability, Assessment, Screening, Systematic review

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## **1. Introduction**

The ICD-10 Classification of Mental and Behavioural Disorders guidelines (World Health Organisation, 1992) define dementia as ‘a syndrome due to disease of the brain, usually of chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The impairments of cognitive function are commonly

accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation'. There is no modified definition of dementia for those with an intellectual disability (ID). Dementia is not a disease in itself, but rather the term used to describe a number of symptoms and features which co-exist in an accepted pattern of brain degeneration. Dementia is caused by a number of conditions and often these specific 'types' of dementia are named after their cause. Common types of dementia include Alzheimer's disease, vascular dementia, dementia with lewy bodies, frontotemporal dementia and mixed dementia where both Alzheimer's and vascular features can be observed (Denning and Babu Sandilyan, 2015).

There is no one accepted psychometric tool for the assessment of dementia in people with ID, either observer-rated or self report. Neuropsychological tools often used to screen for dementia in the general adult population such as the Mini Mental State Examination (MMSE) (Folstein, 1987) or the Addenbrookes Cognitive Examination – 3<sup>rd</sup> Edition (ACE) (Hodges, 2012) cannot be used for people with ID as they assume a pre-morbid level of functioning within the average range; screening using such tools in people with ID would result in difficulties delineating pre-existing cognitive impairment from that associated with a dementing process (Deb et al, 2007a). For these reasons many researchers regard tests and criteria available for people without ID to be not applicable to those with ID (Prasher et al, 2004). One further key difficulty in screening and diagnosing dementia in this population is

the greater probability of physical health conditions in people with ID that can in some cases mimic dementia (Deb et al., 2007b). In those with Down Syndrome (DS), the risk of developing these health conditions, which include cardiac problems, thyroid disorders, sensory impairments, reduced muscle tone and Alzheimer's type dementia (ATD), at an earlier age is increased (Smith, 2001). This has major implications for potential differential diagnoses and what might usefully be included within screening and diagnostic tests as part of the wider diagnostic process.

### **1.1 Screening in Intellectual Disability**

Given this context, there has been a concerted effort among clinicians working with individuals with ID to develop tools that bridge the existing gaps and allow for accurate screening and timely diagnosis. In a recent systematic review, Zeilinger et al. (2013a) found 114 available tools for the purpose of dementia screening. Of these, 79 instruments were to be completed directly by the person with ID and 35 were informant-based instruments. An additional four test batteries were identified.

Zeilinger et al. (2013a) noted that the intention of the review was to provide an overview of available tools, acknowledging that they did not evaluate the instruments collected or examine the psychometric properties or other characteristics. However, reviewing in more detail the strengths and limitations across the available tools may allow for a comparison

between specific tools. Furthermore, it might highlight specific areas for empirical research. Thorough analysis of the individual component parts or items included in the tools might identify those that are most likely to be helpful in dementia screening in this population. It has been argued that it is unlikely that a single tool can be found to accurately and reliably detect dementia in people with ID (Prasher et al, 1995). However, if the most predictive component sub-scales or individual items of the existing individual tools can be integrated, this may lead towards the development of a more reliable dementia screening tool in ID populations.

The systematic review presented here replicates and extends the search strategy used by Zeilinger et al. (2013a) to identify studies which have used any of four specific informant-based assessment tools. The tools chosen for review here are highlighted in the joint British Psychological Society (BPS) and Royal College of Psychiatrists (RCP) guideline ‘Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia’ (BPS, 2009), as examples of best practice for assessing dementia. These are tools clinicians are likely to consider when screening for dementia in people with ID within a UK context and include the Dementia Questionnaire for People with Learning Disabilities (DLD; Evenhuis et al, 2007); The Dementia Scale for Down Syndrome (DSDS; Gedye, 1995); Adaptive Behaviour Dementia Questionnaire (ABDQ; Prasher et al, 2004); Dementia

Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID; Deb et al, 2007a).

The DLD (Evenhuis, 2007) formerly known as the Dementia Questionnaire for People with Mental Retardation (DMR) is a screening tool used to assist in the early detection of dementia in people with a learning disability. First developed in 1980, it is completed by a family member or carer often assisted by a healthcare professional. The DLD consists of 50 items which are sub-divided into eight separate subscales. The following subscales make up the Sum of Cognitive Scores: short term memory; long-term memory; spatial and temporal orientation. The remaining sub scales make up the Sum of Social Scores: speech; practical skills; mood; activity and interest and behavioural disturbance. The items assess for the presence of a particular behaviour corresponding to the individual subscales using a Likert scale with three response categories: 0 points=no deficit, 1 point =moderate deficit, 2 points = severe deficit; and therefore higher scores correspond to more severe deterioration. For example, item 2 states remembers where he/she put something away a short time ago (no longer than half an hour ago), can be scored 0 = normally yes, 1=sometimes and 2=normally no. The DLD is widely used throughout the United Kingdom and Europe (BPS, 2009).

The DSDS (Gedye, 1995) was developed to provide a means to assess cognitive deterioration in adults with prior cognitive impairment. The tool was intended to specifically assess for dementia in people with DS, though the NICE guidelines (2006) suggest it can also be used with people with ID who do not have DS. It is a 60-item informant based tool and the items are grouped into three separate categories identifying characteristics of dementia as ‘early stage’, ‘middle stage’ and ‘late stage’. As an example, to meet criteria for ‘early stage’, the



person must demonstrate a minimum of three losses in the cognitive area, defined as the Cognitive Cut-off score (Jozsvai et al., 2009).

The DSQIID (Deb et al, 2007a) is an informant-rated dementia screening tool comprising of 43 questions across three separate sections. In Part 1: Level of 'Best' Ability, the DSQIID attempts to give an indication of both the presence of dementia and its severity by categorising it as early, middle or late stage. Part 2 and Part 3 comprise a time course of the persons decline and a section detailing information on differential diagnosis.

The ABDQ (Prasher et al, 2004) is a 15-item questionnaire designed to detect change in adaptive behavior. It was developed from an earlier screening tool known as the AAMD Adaptive Behaviour Scale (Nihira et al, 1974) and was intended specifically for screening for dementia in Alzheimer's disease. It compares a person's current presentation to his/her previous level of social functioning. The tool provides cut-offs for dementia and a rating on severity as follows: mild –  $\geq 78-89$ , moderate –  $\geq 90-99$ , severe -  $\geq 100$ ). The ABDQ also gives criteria for the presence of Alzheimer's disease specifically and a rating on severity.

Zeilinger et al., (2013a) recommended that all dementia screening tools identified in their review should be evaluated to identify their characteristics and psychometric properties. The current review represents a first step towards this recommendation by reviewing these four recommended tools outlined above. Specifically, this review aims to identify 1) what is the sensitivity and reliability of the four dementia screening tools? 2) what are the characteristics of the tools such as aetiology of the target group and ease of use? 3) what is the evidence base for the use of these tools with an ID population? and 4) what is the quality of the studies

contributing to that evidence base?

## **2. Method**

### **2.1 Literature Search**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA Group, 2009) was used to inform the methods employed in writing this review. A systematic literature search was conducted across the following databases: CINAHL, PsycInfo, Medline, Scopus and Web of Science. The search string included the following terms for (1) output of interest (e.g. assessment instrument, diagnostics or screening), (2) measure of interest (dementia, Alzheimer's disease). The search was performed once for the (3) specified population (intellectual disability, mental retardation, learning disability) and a second time for persons with Down syndrome (Down syndrome, trisomy 21). The final search string included the inclusion of four specific assessment measures highlighted as best practice measures for use in screening dementia in this population (British Psychological Society, 2009). Table 1. shows the detailed search strategy using Boolean operators. The final search string included all terms for output, measure, population and specific tools (1 AND 2 AND 3 AND 4) and was used in title, abstract and keyword without setting any limits.

## **2.2 Inclusion and Exclusion Criteria**

Relevant studies were identified and selected on the basis of the following inclusion criteria: 1) studies focused on assessing dementia in people with ID, and 2) studies in which one of four specific measures has been used (i.e. DLD, DSDS, DSQIID, ABDQ). The present review used five exclusion criteria: 1) classification systems used to make a diagnosis such as the Diagnostic and Statistical Manual of Mental Disorders (DSM), 2) scales focused on mood disorders or Parkinsons disease and 3) medical tests (e.g. genetic marker tests, PET, fMRI), (taken from Zeilinger et al, 2013a) 4) studies that used the DLD, DSDS, DSQIID or the ABDQ but did not report on their psychometric properties and 5) existing reviews or assessment guidelines for assessment of dementia in people with learning disability which discussed assessment instruments.

## **2.3 Coding of Dementia Screening Tools and Relevant Studies**

Within this review a two-step process of rating was adopted. Firstly, all studies identifying the use of at least one of the dementia screening tools selected for inclusion in the search (i.e. DLD, DSDS, DSQIID, ABDQ) were collated. Information about the tools characteristics and psychometric properties, contained within these studies, was extracted and rated according to the Characteristics of Assessment Instruments in Persons with Intellectual Developmental Disorders (CAPS-IDD) (Zeilinger et al, 2013b). The CAPS-IDD evaluates and describes instruments that identify psychiatric disorder among people with intellectual developmental

disability. It is sub-divided into two sections known as Part 1: Conceptual and Measurement Model and Part 2: Psychometric Properties. In Part 1: Conceptual and Measurement Model there are three further sub-sections. These are Section B: Basic Information, Section T: Test Development and Section C Measurement Characteristics. In Part 2: Psychometric Properties there are five further sub-sections. There are Section V: Validity, Section R: Reliability, Section O: Objectivity of Application, Section N: Objectivity of Interpretation, Norming and Fairness. A comprehensive review of the development of the CAPS-IDD and further information relating to individual subsections can be found in Zeilinger et al. (2013b). The aim of the CAPS-IDD is to provide a structured overview of instruments and allow for comparison across measures on both quality and individual features. The coded CAPS-IDD schedules for the four measures included within this review can be found in the Appendix section (Appendix 6). Once the screening tools had been coded using the CAPS-IDD, the second part of the review involved rating the quality of the individual papers related to the four measures. This was done using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Qualsyst) (Kmet et al, 2004). Qualsyst is a structured and replicable system for scoring, in this case quantitative studies, which aims to ensure a minimum quality standard. The Qualsyst includes two checklists for both quantitative and qualitative studies. For the present review, the checklist for assessing the quality of quantitative studies was used and includes 14 items such as 'is the question/objective sufficiently described?', 'sample size appropriate' and 'conclusions

supported by the results'. The quality assessment score is obtained by rating each study according to the degree to which they met these 14 criteria. Possible scores included 'yes'=2, 'partial'=1 and 'no'=0. Items that were not applicable to a particular study design were marked as such and excluded from the total summary score. To obtain the final summary score the applicable item scores were then added together and divided by the total possible score of 28. For further information on scoring or for a full description of the 14 criteria please see Kmet et al (2004)'.

### **3. Results**

#### **3.1 Literature Search**

The literature search yielded a total of 106 records. After excluding duplicates, 77 remained. These were screened by reviewing titles and abstracts to check the relevance of each study. A further 51 records were excluded at this stage, leaving a total of 26 studies reviewed as full text articles. This yielded a total of 16 studies for inclusion in the final review. Of these, 13 studies referred to the DLD, 1 to the ABDQ, and 1 to the DSQIID. One paper referred to both the DLD and the DSDS. A substantial proportion of the studies included (6/16, 37.5%) reported single completion, rather than longitudinal data. Figure1. gives an overview of the search strategy and its results.

Using the CAPS-IDD (Zeilinger et al., 2013b) to extract and rate the four tools from the

available papers yielded detailed information relating to individual characteristics as well as the psychometric properties. Individual characteristics within the CAPS-IDD refers to basic information such as the concept to measured, level of ID and age of the target group, as well as information on test development and measurement. Summary evidence from the CAPS IDD are provided in the following tables for each of the four screening tools, Tables 1, 2, 3, and 4. The Qualsyst (Kmet et al, 2004) gave a further indication of the quality of the studies identified. Fifty percent sample of the included papers were rated by two researchers independently. There was substantial agreement between the two raters ( $k=0.788$  ( $p<0.0001$ ), 95% CI (0.681 – 0.895) (Landis and Koch, 1977). Final Qualsyst ratings are provided in Appendix 1.

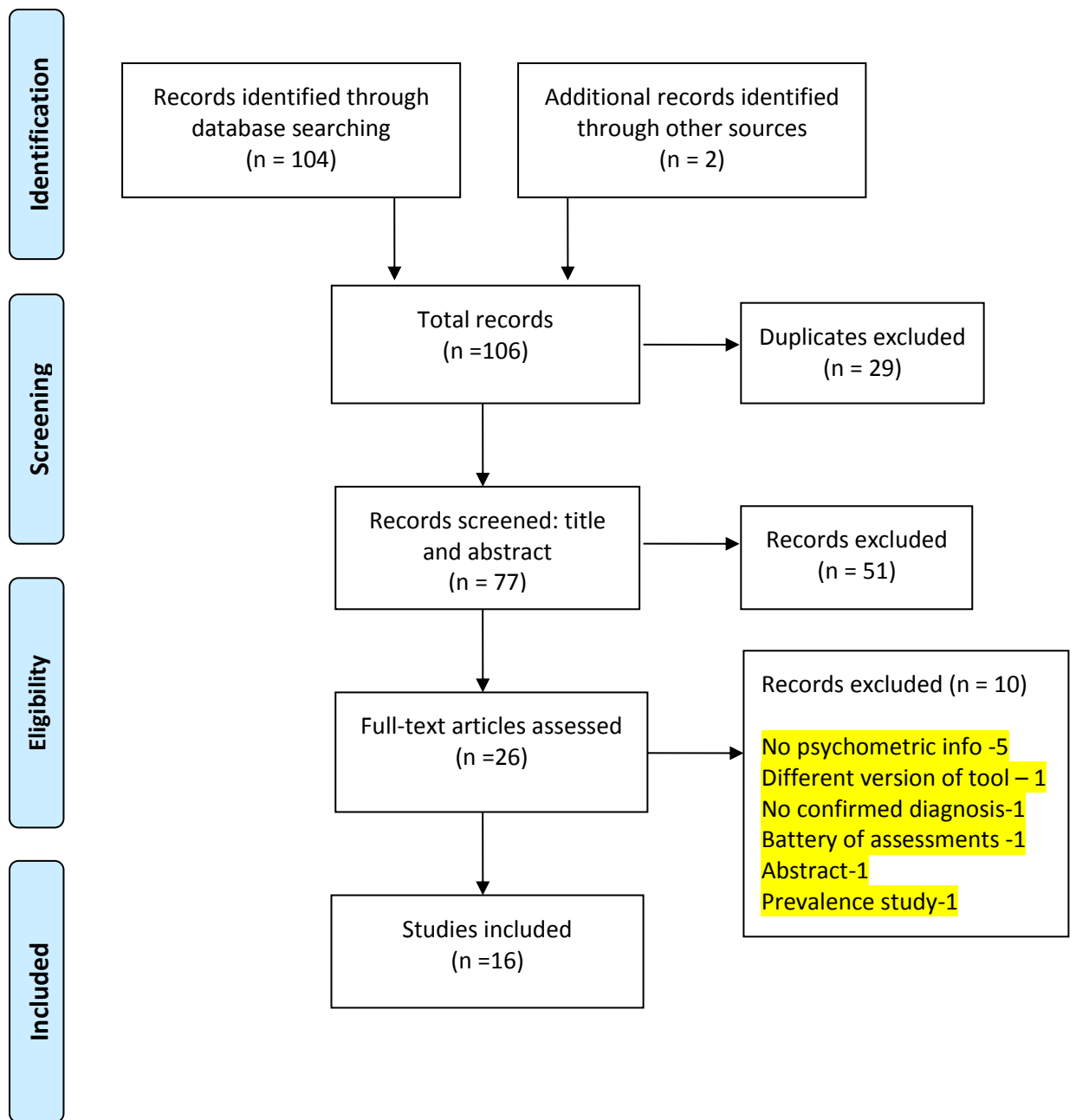


Figure 1. Prisma Diagram of Search Strategy

### 3.2 Quality Assessment

CAPS-IDD Summary of Findings Table – Dementia Questionnaire for Persons with Learning Disabilities (DLD)	
Part 1. Conceptual and Measurement Model	
<p><b><u>B: Basic Information</u></b>            B1: Concept to be measured: <b>Dementia</b>            B2: Level of IDD: <b>Mild. Moderate, Severe</b>            B3: Aetiology of target group: <b>None</b>            B4: Age of Target group: <b>Adulthood, Elderly</b>            B5: Primary purpose/recommendation for use: <b>Screening</b>            B6: Available modes of administration: <b>Single setting, paper-pencil, communication aids not available</b>            B7: Respondent requirements: <b>Person with IDD is not a respondent. Caregiver (e.g. direct care staff, family carer, teacher)</b>            B8: Competence Level needed for administration: <b>Psychologist, Psychiatrist</b></p>	<p><b>Summary of Findings</b></p> <p>The DLD is a dementia screening tool for use in the mild, moderate, severe range of IDD. It is not applicable to those with profound IDD (with a developmental age of lower than 2 years) or to persons with severe IDD (with a developmental age of 2-3 years) combined with severe other disabilities such as motor impairment or hearing loss. Patients with Down syndrome were excluded from some studies but included in others. A first evaluation involved 98 'ageing residents'. Another study population consisted of 271 'older people'. Pearson clinical state the age range as adult. The DLD is a screening instrument to be used as part of a comprehensive assessment to identify those who require further specialist diagnostic assessment. It is administered single setting using paper and pencil. There is no computer based alternative or accompanying visual aids or symbols. The person with IDD is not a respondent. It should be completed by a family or staff member who is familiar with the person. Questions should be guided by an appropriately qualified professional.</p>
<p><b><u>T: Test Development</u></b>            T1: Main underlying theory for generating items: <b>Behavioural, other (cognitive)</b>            T2: Experts involved in test development: <b>Mental health professionals</b>            T3: Based on classification models: <b>DSM-IV</b></p>	<p><b>Summary of Findings</b></p> <p>The main underlying theory used in generating the items is behavioural and cognitive with the items organised into Sum of Cognitive Scores and Sum of Social Scores. The developers of the tool are mental health professionals. The tool has been based on the DSM-III-R and later the DSM-IV criteria.</p>
<p><b><u>C: Measurement</u></b>            C1: Item content: <b>Problem behaviour, adaptive behaviour, emotional e.g. feelings, cognitive abilities</b>            C2: Item coding: <b>Polytomous (includes Likert scale) Presence (does the person show the symptom/behaviour at all)</b>            C3: Timeframe: <b>More than one month but less than 6 months</b>            C4: Floor/ceiling effects: <b>No information</b>            C5: Responsiveness: <b>Yes, recommended to detect changes</b></p>	<p><b>Summary of Findings</b></p> <p>The items are organised into Sum of Cognitive Scores (SCS) and Sum of Social Scores (SOS). The SCS includes short-term memory, long-term memory and spatial and temporal orientation. The SOS includes speech, practical skills, mood, activity and interest and behavioural disturbance. The response format is polytomous and assesses for presence i.e. does the person show the symptom/behaviour at all. Most items have three response categories: 0-no deficit, 1-moderate deficit, 2</p>



	severe deficit. Higher scores correspond to more severe deterioration. The questionnaire requires that behaviour during approximately the last two months be observed and scored. The DLD has been shown to detect change in functioning.									
Part 2: Psychometric Properties										
<b><u>V: Validity</u></b> V1: Criterion validity: <b>Sensitivity</b> V2: Content validity: <b>No information</b> V3: Construct validity: <b>No information</b> V4: Face validity: <b>No information</b>	<b>Summary of Findings</b>  <b>Application of the cut-off criteria agreed resulted in a sensitivity and specificity as follows at the 95% confidence level.</b> <table><tr><td></td><td><b>Sensitivity</b></td><td><b>Specificity</b></td></tr><tr><td>70+</td><td>7/7(100%) (59-100)</td><td>19/26 (73%) (52-88)</td></tr><tr><td>Down syndrome</td><td>8/8(100%) (63-100)</td><td>27/36 (75%) (58-88)</td></tr></table> <b>Prasher et al (1997), using longitudinal data reported a sensitivity of 60% and a specificity of 67%.</b>		<b>Sensitivity</b>	<b>Specificity</b>	70+	7/7(100%) (59-100)	19/26 (73%) (52-88)	Down syndrome	8/8(100%) (63-100)	27/36 (75%) (58-88)
	<b>Sensitivity</b>	<b>Specificity</b>								
70+	7/7(100%) (59-100)	19/26 (73%) (52-88)								
Down syndrome	8/8(100%) (63-100)	27/36 (75%) (58-88)								
<b><u>R: Reliability</u></b> R1: Internal consistency: <b>No information</b> R2: Reliability: <b>Interrater</b> R3: Measurement error: <b>No information</b>	<b>Summary of Findings</b>  <b>Interrater reliability was measured using the Pearson correlation coefficient for the different subscales. These varied between 0.44 and 0.94. Short-term memory 0.84, long-term memory 0.87, orientation – speech 0.68, practical skills 0.94, mood/activity of interest 0.74. Two correlations were slightly low: speech and behavioural disturbance.</b>									
<b><u>O: Objectivity of Application</u></b> O1: Application: <b>Comprehensive manual available</b> O2: Coding: <b>Comprehensive manual available</b>	<b>Summary of Findings</b>  <b>A fully comprehensive manual is available (Evenhuis, 2007). Evenhuis, H.M., &amp; Kengen M.M.F. &amp; Eurlings. H.A.L. (2007). Dementia Questionnaire for People with Learning Disabilities: UK Adaptation of the Dutch Instrument.</b>									
<b><u>N: Objectivity of Interpretation, Norming and Fairness</u></b> N1: Norms: <b>Level of IDD</b> N2: Cut-offs: <b>Rationale and procedures for determining cut-offs present</b> N3: Fairness: <b>Other aspects</b>	<b>Summary of Findings</b>  <b>Normed on mild-moderate IDD population. Provisional cut-offs for single completion were determined following the first prospective evaluation study. These were re-evaluated following a second study and finalised. In the updated manual (Evenhuis, 2007) noted that as the provisional criteria were based on single completion their use may have led to unreliable results. Therefore they were not included in the manual. The assessment criteria for ‘dementia’ based on score change as compared with the original DLD score is: an increase in the Sum of Cognitive Scores (SCS) of 7 points or more and/or an increase in the</b>									

	Sum of Social Scores (SOS) of 5 points or more, independent of the original level of learning disability.
<b>F: Feasibility</b> F1: Missing values: <b>No information</b> F2: Ease of administration/burden: <b>Time needed for completion, reading and/or comprehension level, special requirements or requests made of respondent, evidence that instrument places no undue physical or emotional strain on respondent, time needed for scoring/interpretation</b> F3: Value: <b>for health professionals (e.g. psychologist, , psychiatrist, for persons with IDD, for caregiver (direct-care staff, family carer)</b> F4: Acceptability: <b>for health professional (e.g. psychologist, psychiatrist)</b> F5: Availability: <b>Not free, published as test (manual)</b>	<b>Summary of Findings</b>  Reading and comprehension level for the respondent is minimal and no special requirements or requests are made of them. The instrument places no undue physical or emotional strain on the respondent. Pearson clinical state that the questionnaire takes 10-20 minutes to complete. The DLD is one of the most commonly used tools within the UK and according to the published manual (Evenhuis, 2007) is high-ranking in recommendations for diagnostic batteries. The tool can be considered an acceptable questionnaire for use by health professionals for dementia screening. The questionnaire can be purchased at <a href="http://www.pearsonclinical.co.uk">www.pearsonclinical.co.uk</a> . Complete kit price currently £129.50.

Table 1. Summary Findings for CAPS-IDD – DLD

CAPS-IDD Summary of Findings Table – Dementia Scale for Down Syndrome (DSDS)	
Part 1. Conceptual and Measurement Model	
<b>B: Basic Information</b> B1: Concept to be measured: <b>Dementia</b> B2: Level of IDD: <b>Severe, profound</b> B3: Aetiology of target group: <b>Trisomy 21</b> B4: Age of Target group: <b>Adulthood</b> B5: Primary purpose/recommendation for use: <b>Diagnosis</b> B6: Available modes of administration: <b>Single setting, paper-pencil, communication aids not available</b> B7: Respondent requirements: <b>Person with IDD is not a respondent, Health professional (e.g. psychologist, psychiatrist, nurse)</b> B8: Competence Level needed for administration: <b>Psychologist</b>	<b>Summary of Findings</b>  The DSDS was developed as a tool to assess cognitive deterioration in adults with prior intellectual developmental disability (IDD). It was specifically intended for use with those in the lower ranges of functioning and was standardised and validated on individuals with Down syndrome in the severe and profound ranges of intellectual functioning. The published manual, in a note added in January 2007, states that the tool may or may not be useful for individuals in the mild moderate range of functioning and that this would have to be confirmed by appropriate studies. However the author noted that tool has proven equally sensitive for assessing dementia in developmentally disabled adults without DS. The DSDS was designed to diagnose the absence or presence of dementia and to rate its severity. It is administered single setting using paper and pencil. There is no computer based alternative or accompanying visual aids or symbols. The person with IDD is not a respondent. The tool relies on information obtained from caregivers in a structured interview. The author is clear that only psychologists and psychometrists trained in standardised testing and with experience in

	administering intelligence tests are permitted to use this psychological assessment tool.
<b><u>T: Test Development</u></b> T1: Main underlying theory for generating items: <b>Behavioural</b> T2: Experts involved in test development: <b>Mental health professionals, persons with IDD (e.g. focus group, pre-testing)</b> T3: Based on classification models: <b>DSM</b>	Summary of Findings
	<b>The main underlying theory used in generating the items is behavioural with the scale incorporating behaviours commonly found in developmentally disabled adults. Other items were included to detect changes in which might indicate loss of functioning for that individual. The developers of the tools are mental health professionals and persons with IDD were also used in pre-testing in a prospective longitudinal study. The tool is consistent with the related DSM criteria.</b>
<b><u>C: Measurement</u></b> C1: Item content: <b>Problem behaviour</b> C2: Item coding: <b>Dichotomous (yes/no; right/wrong), presence (e.g. of a skill, problem, symptom, presence (does the person show the behaviour at all)</b> C3: Timeframe: <b>6 months, more than months</b> C4: Floor/ceiling effects: <b>No information</b> C5: Responsiveness: <b>Yes, recommended to detect changes</b>	Summary of Findings
	<b>The DSDS contains items that describe behaviours commonly found in developmentally disabled adults. Other items have been designed to detect changes with represent loss of functioning for that individual. It uses four terms to classify these features: typical, non-applicable, present, absent. The author of the tool suggests follow-up every 6-12 months to ensure detection of potential changes and to accurately detect the time of onset of dementia.</b>
Part 2: Psychometric Properties	
<b><u>V: Validity</u></b> V1: Criterion validity: <b>Concurrent, Sensitivity</b> V2: Content validity: <b>No information</b> V3: Construct validity: <b>Other</b> V4: Face validity: <b>Face validity rated by author</b>	Summary of Findings
	<b>The author completed a concurrent study on 1993. Dementia assessments were completed independently and later compared with the psychiatrist's dementia ratings yielding a kappa coefficient of 0.81. The author reported that evidence for content validity was not specifically collected. However noted that DSDS items would reflect deterioration in the relevant domains of cognitive functioning. One estimate of construct-related validity is the relationship between known final outcome and earlier half scores on a test. Half of the sample of 60 older adults with Down syndrome progressed from varying levels of cognitive ability to being totally unable to perform any tasks requiring memory, comprehension or language. 100% of those people had earlier met the tools criteria for onset of cognitive decline and progression to middle and late stages. Face validity is rated by the author. Deb and Braganza (1999) reported a sensitivity of 0.89 and a sensitivity of 0.85.</b>

<b><u>R:Reliability</u></b> R1: Internal consistency: <b>No information</b> R2: Reliability: <b>Interrater</b> R3: Measurement error: <b>No information</b>	Summary of Findings
	<b>The interrater reliability yielded a kappa coefficient of 0.91.</b>
<b><u>O:Objectivity of Application</u></b> O1: Application: <b>Comprehensive manual available</b> O2: Coding: <b>Comprehensive manual available</b>	Summary of Findings
	<b>A fully comprehensive manual is available. It can be purchased by contacting the author, sending the appropriate forms and payment. Details can be found on the website <a href="http://www.gedye.ca">www.gedye.ca</a>.</b>
<b><u>N: Objectivity of Interpretation, Norming and Fairness</u></b> N1: Norms: <b>Year in which norm sample was tested, size of norm sample, important characteristics of norm sample (e.g. representative for target population, identify language or ethnic groups, sex, level of IDD</b> N2: <b>Cut-offs: Rationale and procedures for determining cut-offs</b> N3: Fairness: <b>No information</b>	Summary of Findings
	<b>The tool was initially normed on a sample which included 60 adults with IDD and Down syndrome. A group of adults without IDD and Down syndrome. Items are grouped within stages: early, middle, late and very late. A complex description of scoring criteria is contained within the manual.</b>
<b><u>F: Feasibility</u></b> F1: Missing values: <b>Other</b> F2: Ease of administration/burden: <b>Other</b> F3: Value: <b>For health professionals (e.g. psychologist, psychiatrist), person with IDD</b> F4: Acceptability: <b>For health professionals (e.g. psychologist)</b> F5: Availability: <b>Not free, can be requested from the author</b>	Summary of Findings
	<b>The author acknowledged missing data but noted that split-half reliability was not feasible. The DSDS test booklet was designed for repeated use. This makes 6 monthly or annual comparisons easier and the author suggests this can aid early detection of dementia. The tool should be used by a clinician in a structured interview after having studied the manual. It is not a questionnaire to be given to informants to complete. The tool is an acceptable questionnaire for use by health professionals with the appropriate qualifications. A fully comprehensive manual is available. It can be purchased by contacting the author, sending the appropriate forms and payment. Details can be found on the website <a href="http://www.gedye.ca">www.gedye.ca</a>.</b>

Table 2. Summary findings CAPS-IDD - DSDS

<b>CAPS-IDD Summary of Findings Table – Dementia Questionnaire for Individuals with Intellectual Disabilities (DSQIID)</b>
Part 1. Conceptual and Measurement Model

<p><b><u>B: Basic Information</u></b>  B1: Concept to be measured: <b>Dementia</b>  B2: Level of IDD: <b>Mild, Moderate, Severe, Profound</b>  B3: Aetiology of target group: <b>Trisomy 21</b>  B4: Age of Target group: <b>Adulthood</b>  B5: Primary purpose/recommendation for use: <b>Screening</b>  B6: Available modes of administration: <b>Single setting, paper-pencil, communication aids not available</b>  B7: Respondent requirements: <b>Person with IDD is not a respondent. Caregiver (e.g. direct care staff, family, carer, teacher)</b>  B8: Competence Level needed for administration: <b>Direct care staff, other</b></p>	<p>Summary of Findings</p> <p>The DSQIID is an observer rated dementia screening tools for use with adults with intellectual disabilities. The author suggests that the tool can be used equally effectively among all adults with intellectual disabilities, though the measure was only tested on a sample of adults with Down syndrome. It is administered single setting using paper and pencil. There is no computer based alternative or accompanying visual aids or symbols. The person with IDD is not a respondent. The DSQIID is observer rated and should be completed by carers of people with Down syndrome who have known the person for at least 6 months in order to be effective. It is also noted that the person should have witnessed change since the onset of dementia. The author is clear that the questionnaire is for use by carers. They do not specify that the tool should be guided by a health professional.</p>
<p><b><u>T: Test Development</u></b>  T1: Main underlying theory for generating items: <b>Behavioural</b>  T2: Experts involved in test development: <b>Mental health professionals, direct care staff, family carers</b>  T3: Based on classification models: <b>ICD</b></p>	<p>Summary of Findings</p> <p>The main underlying theory used in generating the items is behavioural with the measure specifically assessing adaptive behaviour. The developers of the tool were mental health professionals, direct care staff and family members. Carers of 24 adults with Down syndrome were interviewed to and the data analysed to qualitatively derive 53 items for inclusion in the questionnaire. The DSQIID has been based on the ICD-10 criteria.</p>
<p><b><u>C: Measurement</u></b>  C1: Item content: <b>Problem behaviour</b>  C2: Item coding: <b>Polytomous (included Likert scale) Presence (e.g. skill, problem, symptom)</b>  C3: Timeframe: <b>6 months</b>  C4: Floor/ceiling effects: <b>Other</b>  C5: Responsiveness: <b>Yes, recommended to detect changes</b></p>	<p>Summary of Findings</p> <p>The DSQIID is divided into three parts. Part 1. asks about the ‘best’ ability the person has or has had. Part 2. contains 43 questions about behaviour or symptoms that are usually associated with dementia in adults with Down syndrome. It is a polytomous scale and is scored on a four-point scale: ‘always has been the case’, ‘always but worse’, ‘new symptoms’ and ‘does not apply’. Part 3. contains 10 questions, all of which are comparative; for example ‘speaks(signs) less and ‘seems generally more tired’. A response of ‘yes’ is scored 1 and a response of ‘no’ is scored 0. Scores from part 2 and 3 are added to give a total score. The 53 items include factors such as loss of memory, confusion, loss of skills, social withdrawal, behavioural changes, psychological symptoms, sleep disturbance and speech abnormalities. The authors state that the respondent should only report those behaviours which that have existed for at least 6 months, though they acknowledge that they did not themselves apply this criterion. The paper states that the Likert scale scoring system was adopted to overcome the floor effect of the existing dementia screening tools which score current behaviour. The DSQIID measures changes in behaviour.</p>

Part 2: Psychometric Properties	
<b><u>V: Validity</u></b> V1: Criterion validity: <b>Area under the ROC, sensitivity/specificity</b> V2: Content validity: <b>Concerning relevance of items, concerning comprehensiveness of items</b> V3: Construct validity: <b>Factor analysis (CTT)</b> V4: Face validity: <b>Face validity rated by the authors, face validity rated by caregiver</b>	Summary of Findings
	<b>Receiver operating characteristic (ROC) analysis was used on data from those who were examined by a clinician. Use of an overall score of 20 as a screening cut-off provided a sensitivity of 0.92, specificity 0.97, a positive likelihood ratio of 31 and a negative likelihood ratio of 0.08. The authors reported that the checked whether any items were repeatedly missed by carers or providing the same answer. When preparing the questions they took into account interpretability, ambiguity, carers reading level, avoidance of double-barrelled questions, jargon, value-laden words, positive and negative wording and the length of the items. By adopting a 'bottom up' approach that incorporated the views of carers, the authors assert that this has ensured good face validity. A forced four factor analysis was conducted which included over 57% of the variance. The last 10 items of the questionnaire were excluded from this analysis as they were rated on a two-point system.</b>
<b><u>R: Reliability</u></b> R1: Internal consistency: <b>Cronbach's alpha (CTT)</b> R2: Reliability: <b>Test-retest, interrater</b> R3: Measurement error: <b>Test-retest, interrater</b>	Summary of Findings
	<b>Chronbachs alpha for all 53 items on the DSQIID is 0.91. The authors also report that they used data from all participants to analyse test-retest and interrater reliability. The intraclass correlation for the test-retest reliability (n=52) was 0.95.</b>
<b><u>O: Objectivity of Application</u></b> O1: Application: <b>Some instructions available (e.g. published paper)</b> O2: Coding: <b>Some guidelines available (e.g. published paper)</b>	Summary of Findings
	<b>The published paper (Deb et al, 2007a) gives brief instructions on the structure, administration and scoring.</b>
<b><u>N: Objectivity of Interpretation, Norming and Fairness</u></b> N1: Norms: <b>Year in which the norm sample was tested, size of norm sample, important characteristics of norm sample, aetiology (e.g. specific syndromes),</b> N2: Cut-offs: <b>Rationale and procedures for determining cut-offs</b> N3: Fairness: <b>Other aspects</b>	Summary of Findings
	<b>The DSQIID was administered to carers of 193 adults with Down syndrome , 117 whom were examined by clinicians who confirmed a diagnosis of dementia for 49 according to modified ICD-10 criteria. A total cut-off score of 20 is recommended for screening for adults dementia among adults with Down</b>

	syndrome. However, the authors acknowledge that there may be different cut-off scores for people with severe and profound intellectual disabilities.
<b><u>F: Feasibility</u></b> F1: Missing values: <b>No information</b> F2: Ease of administration/burden: <b>Time needed for completion, reading and/or comprehension level, special requirements or requests made of respondent, evidence that instrument places no undue physical or emotional strain on respondent, time needed for scoring/interpretation, easy to understand instructions</b> F3: Value: <b>for health professionals (e.g. psychologist, , psychiatrist, for persons with IDD, for caregiver (direct-care staff, family carer)</b> F4: Acceptability: <b>for health professional (e.g. psychologist, psychiatrist)</b> F5: Availability: <b>Available for free, can be requested from author</b>	Summary of Findings <b>Reading and comprehension level for the respondent is minimal and no special requirements or requests are made of them. The instrument places no undue physical or emotional strain on the respondent. The authors report that the DSQIID is easy to use, takes approximately 10-15 minutes to complete and can be administered at home or in a clinic setting. They note that the screening cut-off is constant rather than variable and applies to all levels of IDD. They note that the tool is acceptable for health professionals, carers and the individual and that its value is in timely diagnosis and treatment. The questionnaire can be found online for free at the following address:  <a href="http://www.birmingham.ac.uk/Documents/college-les/psych/ld/LDDementiaScreeningQuestionnaire.pdf">http://www.birmingham.ac.uk/Documents/college-les/psych/ld/LDDementiaScreeningQuestionnaire.pdf</a> </b>

Table 3. Summary findings CAPS-IDD - DSQIID

<b>CAPS-IDD Summary of Findings Table – Adaptive Behaviour Dementia Questionnaire (ABDQ)</b>	
Part 1. Conceptual and Measurement Model	
<b><u>B: Basic Information</u></b> B1: Concept to be measured: <b>Dementia</b> B2: Level of IDD: <b>Mild, Moderate, Severe, Profound</b> B3: Aetiology of target group: <b>Trisomy 21</b> B4: Age of Target group: <b>Adulthood</b> B5: Primary purpose/recommendation for use: <b>Screening</b> B6: Available modes of administration: <b>Single setting, paper-pencil, communication aids not available</b> B7: Respondent requirements: <b>Person with IDD is not a respondent. Caregiver (e.g. direct care staff, family, carer, teacher)</b> B8: Competence Level needed for administration: <b>None</b>	Summary of Findings <b>The ABDQ is a dementia screening tool designed specifically to screen for dementia in Alzheimer's disease (DAD) in adults with Down syndrome (DS). The ABDQ can be used in all adults, irrespective of level of IDD. The questionnaire specifically targeted individuals with Down Syndrome. It is administered single setting using paper and pencil. There is no computer based alternative or accompanying visual aids or symbols. The person with IDD is not a respondent. The person with IDD is not a respondent. It should be completed by the principal carer and the author noted that this can be either a family member or paid carer. The author does not specify a specific competence level to be able to administer the measure, though does state that it can be conducted as a semi-interview assessment with the interviewer filling out the scale item-by-item while obtaining information from the person familiar with the person.</b>

<b>T: Test Development</b> T1: Main underlying theory for generating items: <b>Behavioural</b> T2: Experts involved in test development: <b>Mental health professionals</b> T3: Based on classification models: <b>ICD</b>	Summary of Findings
	<b>The main underlying theory used in generating the items is behavioural with the questionnaire specifically assessing adaptive behaviour. The developers of the tool are mental health professionals. The tool has been based on the ICD-10 criteria.</b>
<b>C: Measurement</b> C1: Item content: <b>Adaptive behaviour</b> C2: Item coding: <b>Polytomous (included Likert scale) Presence (e.g. skill, problem, symptom)</b> C3: Timeframe: <b>More than 6 months</b> C4: Floor/ceiling effects: <b>No information</b> C5: Responsiveness: <b>Yes, recommended to detect changes</b>	Summary of Findings
	<b>The ABDQ consists of 15 questions which assess adaptive behaviour. The response format is polytomous and assesses for presence i.e. of a skill or problem. Most items have three response categories and higher scores indicate increasing severity of dementia in AD. No dementia in AD - &lt;78, mild dementia in AD - 78-89, Moderate dementia in AD - 90-99, Severe dementia in AD ≥100. The author reported that the persons included in the study were being followed up on an annual basis and soothe behaviour being observed was across a year period. The ABDQ has been shown to detect change in functioning.</b>
Part 2: Psychometric Properties	
<b>V: Validity</b> V1: Criterion validity: <b>Sensitivity/specificity</b> V2: Content validity: <b>Concerning relevance of items, Concerning comprehensiveness of items</b> V3: Construct validity: <b>Exploratory Factor analysis (for CTT)</b> V4: Face validity: <b>Face validity rated by the authors</b>	Summary of Findings
	<b>Using a cut-off score of greater than 78, sensitivity for the ABDQ in detecting DAD was 89% and a specificity of 94%. The overall percentage correct identification (accuracy) of DAD and non dementia in AD cases was 92%. During development of the ABDQ 31 items appeared to be predictors for dementia in AD. The authors attempted to remove the least amount of items while still obtaining some useful results using logistic regression analysis. After examining correlations between 31 items it was possible to reduce further the number of items to 16. One further question was later excluded as from the analysis as significant proportion (15%) of carers had difficulty answering it. The author notes that the items included in the ABDQ were derived from the Adaptive Behaviour Scale (ABS) (Nihara et al, 1974) and therefore does have good face validity.</b>
<b>R: Reliability</b>	Summary of Findings



R1: Internal consistency: <b>Split-half (CTT)</b> R2: Reliability: <b>Interrater</b> R3: Measurement error: <b>No information</b>	<p>In order to verify face validity of the ABDQ, split half validity was undertaken. The results of the binary logistic regression using the new weighted items gave an overall accuracy of 94%, which is comparable to that found previously. With regard to interrater reliability, the total weighted score from one carer was correlated with that reported by the second carer in 36 cases. Pearson correlation was 0.954 (<math>p&lt;.01</math>). This would suggest good interrater reliability.</p>
<b><u>O: Objectivity of Application</u></b> O1: Application: <b>Some instructions available (e.g. published paper)</b> O2: Coding: <b>Some guidelines available (e.g. published paper)</b>	<p>Summary of Findings</p> <p>The published paper (Prasher et al, 2004) gives brief instructions on the structure, administration and scoring.</p>
<b><u>N: Objectivity of Interpretation, Norming and Fairness</u></b> N1: Norms: <b>Year in which the norm sample was tested, size of norm sample, important characteristics of norm sample, sex, level of IDD, chronological age, aetiology (e.g. specific syndromes), weightings determined using ICD-10 criteria</b> N2: Cut-offs: <b>Rationale and procedures for determining cut-offs</b> N3: Fairness: <b>Gender, age</b>	<p>Summary of Findings</p> <p>In the published paper (Prasher et al, 2004) it is reported that 150 adults participated. Of these 83 (55%) were male and 67 (45%) were female. The mean age of the sample at the start was 44 years (SD11.46, range 16-76 years). All individuals had physical stigmata of DS with 92% trisomy 21 (of 135 tested) and 6% of those tested had translocated form of DS. Sixty (40%) were resident in their family home, 57(38%) in community group homes and 33(22%) resided in the hospital. According to ICD-10 criteria (WHO, 1992) for severity of ID, 27 (18%) of individuals had mild ID, 104 (69%) moderate and 19 (13%) severe ID. The ABDQ has not been tested on non-DS adults with dementia, in persons with deterioration in physical health or onset of non-DAD psychiatric disorders, or investigated for the effects of demographic variables (e.g. age, race).</p>
<b><u>F: Feasibility</u></b> F1: Missing values: <b>No information</b> F2: Ease of administration/burden: <b>Time needed for completion, reading and/or comprehension level, special requirements or requests made of respondent, evidence that instrument places no undue physical or emotional strain on respondent</b> F3: Value: <b>for health professionals (e.g. psychologist, , psychiatrist, for persons with IDD, for caregiver (direct-care staff, family carer)</b> F4: Acceptability: <b>for health professional (e.g. psychologist, psychiatrist)</b> F5: Availability: <b>Available for free, can be requested from author</b>	<p>Summary of Findings</p> <p>Reading and comprehension level for the respondent is minimal and no special requirements or requests are made of them. The instrument places no undue physical or emotional strain on the respondent. The ABDQ is user friendly and takes approximately 10-15 minutes to complete. The ABDQ has been developed from over 10 years of research investigating changes in adaptive behaviour in adults with Down syndrome. The tool can be considered an acceptable F for use by health professionals for dementia screening. A copy of the ABDQ can be obtained from V.Prasher (vprasher@compuserve.com)</p>

Table 4. Summary findings CAPS-IDD ABDQ

Author	Single completion/Longitudinal	Sample Size	Breakdown of Scores (yes=2, partial=1, no=0) by Criteria Number (C)	Qualsyst Final Summary Score
<b>Dementia Questionnaire for Persons with Intellectual Disability (DLD)</b>				
Evenhuis et al (1984)	Single completion	n=98	C1 - 2 C2 - 1 C3 - 1 C4 - 2 C5 - n/a C6 - n/a C7 - n/a C8 - n/a C9 - 2 C10 - 0 C11 - 0 C12 - 0 C13 - 0 C14 - 0	0.28
Kengen et al (1987)	Single completion	n=271	C1 - 2 C2 - 1 C3 - 0 C4 - 2 C5 - n/a C6 - n/a C7 - n/a C8 - n/a C9 - 2 C10 - 2 C11 - 0 C12 - 0 C13 - 1 C14 - 1	0.39
Evenhuis et al(1990)	Longitudinal	n=17	C1 - 1 C2 - 1 C3 - 1 C4 - 2 n/a C5 - n/a C8 - 1 C9 - 1 C10 - 1 C11 - C12 - 0	0.42

			C6 - n/a C7 - n/a	C13 -2 C14 -2	
Evenhuis et al (1992)	Longitudinal	n=139	C1 - 2 C2 - 1 C3 - 2 C4 - 2 C5 - n/a C6 - n/a C7 -n/a	C8 - n/a C9 - 2 C10 - 2 C11 - 1 C12 - 1 C13 - 1 C14 - 1	0.53
Evenhuis (1996)	Longitudinal	n=33	C1 - 2 C2 - 1 C3 -1 C4 -2 C5 - n/a C6 - n/a C7 -n/a	C8 - n/a C9 - 1 C10 - 0 C11 - 0 C12 -0 C13 - 2 C14 - 0	0.32
Thompson et al (1994)	Longitudinal	n=8	C1 - 2 C2 - 1 C3 - 1 C4 - 2 C5 - n/a C6 - n/a C7 - n/a	C8 - n/a C9 - 0 C10 - 0 C11 - 0 C12 - 0 C13 - 0 C14 - 0	0.21
Prasher (1997)	Longitudinal	n=100	C1 - 0 C2 - 0 C3 - 0 C4 - 0 C5 - n/a C6 - n/a C7 - n/a	C8 - 0 C9 - 2 C10 - 2 C11 - 2 C12 - 2 C13 - 2 C14 - 2	0.42
Deb and Braganza (1999)	Single completion	n=62	C1 - 0 C2 - 0	C8 - 0 C9 - 1	0.35

			C3 - 0 C4 - 2 C5 - n/a C6 - n/a C7 - n/a	C10 - 2 C11 - 0 C12 - 1 C13 - 2 C14 - 2	
Hoekman and Maaskant (2002)	Single completion	n=329	C1 - 2 C2 - 2 C3 - 2 C4 - 2 C5 - n/a C6 - 0 C7 - n/a	C8 - 2 C9 - 2 C10 - 2 C11 - 2 C12 - 0 C13 - 2 C14 - 2	0.71
Silverman et al (2004).	Single completion	n=273	C1. 2 C2. 2 C3. 2 C4. 2 C5. n/a C6. 0 C7. n/a	C8. 2 C9. 2 C10. 2 C11. 2 C12. 0 C13. 2 C14. 2	0.71
Strydom et al (2004)	Single completion	n=23	C1 - 2 C2 - 2 C3 - 2 C4 - 2 C5 - n/a C6 - n/a C7 - n/a	C8 - n/a C9 - 1 C10 - 0 C11 - 0 C12 - 1 C13 - 0 C14 - 1	0.39
Jamieson-Craig et al (2010)	Longitudinal	n=154	C1 - 2 C2 - 2 C3 - 2 C4 - 2 C5 - n/a C6 - 2	C8 - 0 C9 - 2 C10 - 1 C11 - 2 C12 - 1 C13 - 2	0.71

			C7 - n/a	C14 - 2	
McCarron et al (2014)	Longitudinal	n=77	C1 - 2 n/a C2 - 2 C3 - 2 C4 - 1 C5 - n/a C6 - n/a C7 - n/a	C8 -  C9 - 1 C10 - 2 C11 - 2 C12 - 0 C13 - 2 C14 - 2	0.57
<b>Dementia Scale for Down Syndrome (DSDS)</b>					
DSDS (original manual)	Longitudinal	n=70	C1 - 2 n/a C2 - 1 C3 - 1 C4 - 2 C5 - n/a C6 - n/a C7 - n/a	C8 -  C9 - 1 C10 - 1 C11 - 0 C12 - 1 C13 - 1 C14 - 1	0.39
Deb and Braganza (1999)	Single completion	n=62	C1. 0 C2. 0 C3. 0 C4. 2 C5. n/a C6. n/a C7. n/a	C8 - 0 C9 - 1 C10 - 2 C11 - 0 C12 - 1 C13 - 2 C14 - 2	0.35
<b>Adaptive Behaviour Dementia Questionnaire (ABDQ)</b>					
Prasher et al (2004)	Longitudinal	n=150	C1 - 2 C2 - 2	C8 - 1 C9 - 2	0.53

			C3 - 1 C4 - 2 C5 - n/a C6 - n/a C7 - n/a	C10 - 1 C11 - 1 C12 - 0 C13 - 2 C14 - 1	
<b>Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)</b>					
Deb et al (2007a)	Longitudinal	n=193	C1 - 2 C2 - 2 C3 - 2 C4 - 2 C5 - n/a C6 - n/a C7 - n/a	C8 - n/a C9 - 2 C10 - 2 C11 - 2 C12 - 2 C13 - 0 C14 - 2	0.64

Table 5. Qualsyst Study Quality Table

## **4. Discussion**

This review aimed to examine the characteristics and psychometric properties of four observer rated dementia screening tools that are recommended for assessing dementia in ID by the (BPS/RCP, 2009). The review is based on Zeilinger et al.'s (2013a) recommendation that an examination of the available dementia screening tools be completed. A sample of the 114 instruments they identified has been reviewed here, going some way towards extending the literature in this domain. Examining the characteristics and psychometric properties of these tools allows for a direct comparison and highlights both the strengths and limitations of the screening tools included. The use of the CAPS-IDD (Zeilinger et al, 2013b) and the Quallsyst (Kmet et al, 2004) in combination, makes it more likely that the findings of this review are robust.

### **4.1 Comparison of Screening Tools: Characteristics and Psychometric Properties**

The studies used to evidence the CAPS-IDD ratings of the four dementia screening tools varied in quality. The range of quality ratings overall was 0.28-0.71 and these results are summarised in table 5. A clear limitation of the available literature however was the high proportion ( 37.5%) of the included studies that either validated or used the dementia screening tools at a single time point. This is contrary to the current accepted standard of administration in assessment of dementia which involves longitudinal assessment over at least two time-points (Evenhuis, 2007). This has implications for how much weight can be

assigned to the conclusions drawn from these studies in particular.

Of the four dementia screening tools, the DLD (Evenhuis, et al, 2007) had the largest evidence base. In total, 13 studies were identified which were either related to its development or it had been used within later studies which reported further useful information in relation to psychometric properties. Six of these studies were based on data gathered from single completion. Quasyst ratings of the studies used to evidence this screening tool ranged from 0.28 to 0.71. In considering the particular strengths of the DLD, it has been shown to be useful to achieve a diagnosis of dementia over time. However, it is important to be aware that the provisional criteria were based on a single completion study (Evenhuis et al, 1984). The author therefore commented in the updated and amended manual (Evenhuis, 2007) that these criteria may have led to unreliable results. Later studies were longitudinal in design allowing for change score criteria to be developed which make the current scoring of the DLD more reliable. The application of these criteria resulted in a sensitivity of 100% and a specificity of 73% for the group of adults with IDD and a sensitivity of 100% and a specificity of 75% for the group of adults with IDD and Down syndrome. Specificity ratings indicate that 27% and 25% of the respective groups would be incorrectly thought to have dementia when using the DLD (false positive). At approximately 1 in 4 this remains a rather high figure and highlights the importance of robust procedures to identify possible differential diagnoses. However, it is important to note that in dementia screening it is a better outcome clinically to identify cases of possible dementia than miss them entirely. In a longitudinal study Prasher et al (1997) reported much lower sensitivity (60%) and a specificity of (67%) prompting their proposal that a higher cut-off score be used. Interrater reliability figures for the DLD varied between the individual subscales, with speech



(Pearson's correlation = 0.68) and behavioural disturbance (Pearson's correlation=0.44) subscales low compared to the others. As the CAPS IDD summary findings table for the DLD highlights, the main underlying theory behind the DLD is behavioural (item T1) and content includes problem behaviour and adaptive behaviour (item C1). Given this, it is of some concern that a higher level of agreement is not reached between raters on the behavioural disturbance subscale particularly. While the DLD appears to have some practical utility, there remain questions regarding its accuracy in screening for dementia.

The DSDS was specifically developed for use within the lower ranges of IDD and was standardised on a population with Down syndrome in the severe and profound range of IDD. The manual (Gedye, 1995) contains an amendment added January 2007 which highlights that that the tool may or may not be useful for people with intellectual disability in the lower ranges of functioning and note that this may be confirmed by appropriate studies. However, there has only been one further study using the DSDS which met this review's inclusion criteria. In a sample of patients with mild, moderate and severe ID, Deb and Braganza (1999) reported a specificity of 0.89 and a sensitivity of 0.85. Broadly, this would mean that the likelihood of a false positive diagnosis using the DSDS is 15%, suggesting that it may be a more accurate tool than the DLD. However, this was a single completion study. The interrater reliability for the DSDS yielded a kappa coefficient of 0.81 (Gedye, 1995). The author of the tool reported on construct related validity stating that half of the sample studied progressed from varying levels of cognitive ability to be unable to perform tasks required memory, comprehension or language. All of these people (100%) had earlier met the DSDS criterion for onset of cognitive decline and progression to middle and late stage dementia. The DSDS has not been published in a peer reviewed journal (BPS, 2009). Overall, the evidence

concerning the DSDS is limited. In addition, the Quallsyst ratings of the two studies related to this tool were relatively low at 0.39 and 0.35 respectively. Further research would likely yield useful data with which to identify component parts of the DSDS that could facilitate greater accuracy in dementia screening in the future.

Only one paper relating to the DSQIID met the inclusion criteria of this review. The DSQIID is an observer rated dementia screening tool and the authors suggest it can be used Deb et al (2007) used for all adults with IDD irrespective of the level of IDD (Deb et al, 2007a). The study used a longitudinal design and was rated as 0.6 on the Quallsyst. This was one of the highest rated papers included within this review. As the CAPS-IDD summary findings table for the DSQIID highlights, the authors of the DSQIID explicitly state that the Likert scale scoring system was deliberately adopted to measure changes in behaviour in an attempt to reduce the likelihood of the floor effects observed in tools which score current behaviour only. A receiver operating curve analysis was used on the data and an overall cut-off score of 20 provided a sensitivity of 0.92 and a specificity of 0.97. This also yielded a positive likelihood ratio of 31 and a negative likelihood ratio of 0.08. Furthermore a forced four factor analysis related to only part 2 of the tool accounted for 57% of the variance. Cronbach's alpha for all 53 items on the DSQIID was 0.91 showing a high level of reliability while the intraclass correlation for test-retest reliability was 0.95. Overall the evidence for the DSQIID suggests that it is a useful and accurate tool to use in dementia screening. The study used is of a high quality and data was gathered longitudinally. However, further studies which confirm these results would allow for greater confidence in the reliability of this tool.

The final tool reviewed was the ABDQ. One study met the inclusion criteria was rated 0.53

on the Quallsyst (Kmet et al, 2004). This is a tool specifically developed to screen for dementia in Alzheimers disease (DAD). The authors state the ABDQ can be used for adults with IDD in the mild-moderate and severe-profound ranges of intellectual functioning (Prasher et al, 2004). Using a cut-off score of greater than 78 as indicative of a possible dementia, sensitivity was reported as 0.89 and specificity at 0.94. The overall percentage of correct identification of dementia in AD and non dementia in AD was 92%. Split half validity was then used to examine the data using amended weightings on particular items, giving a comparable accuracy of 94%. Prasher et al (2004) reports interrater reliability of 0.954. As with the other tools, given the dearth of literature and exploratory studies which investigate the psychometric properties of the ABDQ, further research is required to verify the current findings.

Overall the largest evidence base was found for the DLD, though some of the evidence identified was conflicting. For example, the sensitivity and specificity values varied between studies. In addition, some of the studies reported on only single completion rather than longitudinal data. Given this, and the dearth of an evidence base for the remaining three tools, it is difficult to draw any definitive conclusions about the predictive accuracy of each tool relative to each other. Nevertheless, based on the evidence presented within the CAPS IDD schedules, the most practical tools to use appeared to be the DLD and the ABDQ due in part to the simplicity of administration. The DSQIID and the DSDS have a more complex structure and therefore process for administration. Despite the practicality of both the DLD and the ABDQ, in the case of the ABDQ, the evidence base was limited to a single paper. Further scrutiny of tools with such limited evidence is required to ascertain with greater accuracy their ability to detect dementia in people with intellectual disabilities. Therefore the

current review would suggest that the DLD has the greatest evidence base to support its use as a screening tool within this population, though caution must be exercised given the conflicting nature of some of the evidence presented.

#### **4.3 Strengths and Limitations of Current Review**

The present review has reviewed a sample of the dementia screening tools available for people with a learning disability. The methodology of this review was based on a previous review by Zeilinger et al (2013). While this provided a solid foundation on which to base the current review, the use of the CAPS-IDD, which itself was developed by Zeilinger, as a method of structuring the information has posed some key challenges. While it provided a thorough and relatively easy to collate schedule of the evidence identified, this was countered by its high level of detail required and on occasion repetition. For example, some evidence was presented twice, due to lack of clarity regarding which section was the 'best fit'. This has resulted in the evidence presented in section 3.2 in tables 1-4 being somewhat difficult to summarise. In particular it can be difficult to ascertain which are the most salient pieces of information. This tool has only recently been developed and there are currently no published studies which have used it for the purposes of research or reviewing a particular tool. The Quallsyst, while a useful tool allowing for a numerical comparison across studies, is potentially susceptible to bias. This is largely as a result of it being a subjective view of the authors' perceptions of the key components of study design which they acknowledge (Kmet et al, 2004). A further key limitation of the study is the search strategies narrow focus on four specific tools. A broader approach, perhaps including a greater number of tools used currently in clinical

practice would allow for a greater degree of scrutiny and comparison. However, it was pragmatic to examine those tools most likely to be frequently used within UK clinical psychology settings for the purposes of dementia assessment. The four tools therefore included within the review were selected due to their inclusion in the BPS guidance document Dementia and People with Intellectual Disabilities (2009). BPS guidance notes that these tools can be considered as best practice (BPS, 2009). Despite this, the current review highlights the lack of an evidence base for all tools except the DLD. This calls into question the validity of such tools within clinical practice and perhaps even whether these can indeed be considered as best practice when screening for dementia. It may be more accurate to say that these tools can be considered as best practice when compared to clinical judgment alone or the absence of screening altogether.

## **5. Conclusions**

This systematic review has provided a useful comparison of four commonly used UK dementia screening tools for people with intellectual disabilities. The evidence base for the four dementia screening tools remains limited. There is also a clear requirement for clinicians, working in intellectual disabilities services to complete further validation studies to facilitate greater understanding of the psychometric properties and accuracy of the tools. Ideally such studies would be prospective, and attempt to address the question of which parts or individual items of the existing tools might helpfully be combined to increase the utility and accuracy of dementia screening in this population. Although a substantive undertaking, such work would be an invaluable contribution toward the development of more

accurate screening tools for people with dementia and ID.

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## **AIMS AND HYPOTHESES**

This thesis was an exploratory study. It aimed to investigate patterns in cognitive and social functioning over time in a population of adults with intellectual disability and Down syndrome using data from the Adaptive Behaviour Dementia Questionnaire (ABDQ; (Prasher et al, 2004) and the Dementia Questionnaire for People with Learning Disability (DLD; Evenhuis et al, 2007), formerly known as the Dementia Questionnaire for Persons with Mental Retardation (DMR; Evenhuis et al, 1996). Longitudinal data were examined to ascertain whether the domains covered in these identify differences between those individuals who do develop dementia and those who do not in this population.

The research also aimed to further examine the data to discern whether particular subscales of the DLD are more predictive of dementia than others. A further aim of the research was to compare the dementia screening tools to identify whether one tool, individual sub-scales or a combination of both tools is better able to distinguish between the dementia and no dementia group. Essentially, the study sought to identify whether the data would highlight an observable pattern that distinguishes between normal and abnormal ageing in this population.

It was hypothesised that:

- 1) The mean ABDQ total score will be higher in those who are later diagnosed with dementia.

- 2) The mean DLD total and sub-scale scores will be higher in those who are later diagnosed with dementia.
- 3) The Sum of Cognitive Scores and individual components of this sub-scale (Short-term memory, Long-term memory, Spatial and Temporal Orientation) will be higher in those who are later diagnosed with dementia.
- 4) The Sum of Cognitive Scores and /or individual components of this sub-scale (Short-term memory, Long-term memory, Spatial and Temporal Orientation) will more accurately distinguish between the dementia and no dementia groups than total DLD score alone.
- 5) The 'Sum of Social Scores' or an individual component of this sub-scale (Speech, Practical Skills, Mood, Activity and Interest and Behavioural Disturbance) of the DLD will more accurately distinguish between the dementia and no dementia groups than total DLD score alone.
- 6) An observable pattern will be present which would determine more accurately the onset of an abnormal pattern of ageing, indicative of a possible dementing process.



## **JOURNAL ARTICLE**

The second part of this thesis is a piece of empirical research presented in a journal article style. It is formatted for submission to the Journal of Applied Research in Intellectual Disabilities (JARID). Guidelines for authors for this journal can be found in Appendix 2.

# **An Investigation of Dementia Screening Tools in a Cohort with Down Syndrome and Intellectual Disability**

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*Background:* A population sample of people with Down syndrome and intellectual disability have been studied longitudinally. Data was gathered from their attendance at local health screening clinics for people with Down syndrome and intellectual disability. The study was exploratory, investigating the differences between normal and abnormal ageing in this population.

*Materials and Method:* Total scores on the Adaptive Behaviour Dementia Questionnaire (ABDQ) and total and sub-scale scores on the Dementia Questionnaire for Learning Disability (DLD, formerly the DMR) were collated. Data were examined to identify whether these tools were able to accurately distinguish between those who develop dementia and those who do not. Patterns of change were also examined between groups in order to identify whether the tools or individual subscales of the tools were able to distinguish between normal and abnormal ageing.

*Results:* Results were mixed. Visual inspection of the ABDQ and DLD scores over time showed a clear pattern of more rapidly increasing scores over time in the dementia group compared with the no dementia group. This would suggest that the tools accurately distinguish between the two groups. However, the MANOVA conducted did not reach statistical significance, suggesting either that the study was underpowered, or that the effect was not, in actuality, present. A series of ROC analyses suggested that the ABDQ had poor to fair predictive quality and the DLD worthless to fair predictive quality in identifying dementia in the population sampled.

*Conclusion:* Given the results, it is difficult to draw any definitive conclusions regarding the predictive accuracy of either the ABDQ or the DLD. Further prospective analysis is required utilising a larger sample size.

*Keywords:* dementia, Down syndrome, screening, diagnosis

## 1. Introduction

Down syndrome is the most common genetic cause of mild and severe intellectual disability (Minns, 1997, Coppus et al, 2006) and people with intellectual disabilities (ID) are at increased risk of developing Alzheimer's type dementia (Jervis and Prinsloo, 2007). It is well-established that those with Down syndrome (DS) are more likely to develop Alzheimer's type dementia earlier in their life than those with intellectual disability alone (Bush et al, 2004; McBrien, 2005; Visser, 1997). Depressive illness, hypothyroidism and visual/hearing impairments are also more common in people with Down syndrome and can, in some cases, present much like dementia (Quality Improvement Scotland, 2006, British Psychological Society, 2009), making diagnosis particularly challenging in this group.

Prevalence of dementia has been estimated at 10 percent between the ages of 40-49 and 40 percent per cent between the ages of 50-59 years in adults with Down syndrome (Holland et al, 1998). This is compared to an overall prevalence of 7.2% dementia in the general adult population over 65 (Galeotti et al, 2013). Despite additional health issues and as a result of improved health care and knowledge, the average life expectancy of people with Down syndrome has increased to 50 years of age, with 20 percent of people living beyond 55 years (Holland, 1999). It is predicted that by the year 2020 the proportion of all people over 65 with intellectual disability will have doubled (Janicki and Dalton, 2000). Bolstered by policy drivers such as the Government's White paper 'Valuing People' (Department of Health, 2001), there has been a clear shift within healthcare to consider the holistic health needs in those with intellectual disabilities and Down syndrome in efforts to tackle a growing health divide. Prospective health screening of this group has become embedded in good clinical practice and the benefits of this are well documented in the literature (Webb and Rodgers, 1999; Barr et al, 1999).

While there are established screening tools designed to assess for dementia in the general adult population, the same cannot be said within the intellectual disability population. In a recent study, Zeilinger et al (2013a) reviewed all assessment instruments used to screen for dementia in people with a intellectual disability. It was noted that a number of assessments being used in clinical practice were not originally developed either for people with intellectual disability, or for assessing for the presence of dementia. Pre-existing cognitive impairments further complicate the diagnostic process for those with intellectual disabilities with some pointing towards discrepancies in research in this area a function of this difficulty (Silverman et al, 2013). There is a clear requirement therefore to establish a consistent procedure for dementia screening for people with intellectual disabilities (Matson and Boisjoli, 2009). Zeilinger et al (2013a) recommended using only those tests developed or adapted specifically for individuals with intellectual disability within their review. A key limitation of the review was that it did not evaluate the psychometric properties of the tools, instead making this a recommendation for further research. The current paper adds to the existing literature by beginning the lengthy process of evaluating tools currently used in clinical practice.

## **1.1 Screening Tools**

The screening tools within this study are the Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher et al, 2009) and the Dementia Questionnaire for People with a Learning Disability, (DLD) (Evenhuis, 2007) formerly known as the Dementia Questionnaire for Persons with Mental Retardation (Evenhuis, 1996). These screening tools are two of those recommended by the BPS guidance document 'Dementia and People with Intellectual Disabilities'. A recent review by Zeilinger et al., (2013) recommended that all dementia screening tools are evaluating to identify which are more accurate in correctly identifying dementia in this population.

The ABDQ is a 15-item questionnaire designed to detect change in adaptive behavior. It was developed from an earlier screening tool known as the AAMD Adaptive Behaviour Scale (Nihira et al, 1974) and was intended specifically for screening for dementia in Alzheimers disease. It compares a person's current presentation compared to previous level of social functioning. The tool provides cut-offs for dementia and a rating on severity as follows: mild –  $\geq 78$ -89, moderate –  $\geq 90$ -99, severe -  $\geq 100$ ). The possible score range on the ABDQ is 0-111. The tool has been shown to have good reliability, validity and an overall accuracy of 92% (Prasher et al, 2004). The ABDQ instructs that it should be completed by a caregiver or family member who knows the patient well and has worked or lived with them consistently over time or an experienced clinician.

The DLD is a 50-item carer completed questionnaire divided into eight sub-categories. Three of these sub-categories (Short-term memory, Long-term memory and Orientation) make up the 'Sum of Cognitive Scores'. The remaining five (Speech, Practical skills, Mood, Activity and Interest and Behavioural disturbance) the 'Sum of Social Scores'. Combining 'Sum of Cognitive Scores' and 'Sum of Social Scores' gives the total raw score. The original DMR manual highlights that the cornerstone of diagnosing dementia in people with intellectual disability is a decline in functioning over time (Evenhuis, 1995). The researcher noted that this has important implications for clinical practice, as the tool was anticipated to be most sensitive when used repeatedly, allowing for comparison between assessment points longitudinally, independent of pre-morbid function. Essentially, change score is fundamental to overall diagnostic utility rather than absolute score at one time point. The guidance paper, 'Dementia and People with Learning Disabilities' (British Psychological Society, 2009) notes that the DLD is widely used throughout the UK and Europe to screen for the early detection of dementia

in people with intellectual disabilities. Evenhuis (1992, 1996), found that the DLD had a sensitivity level of up to 100% in identifying dementia and provided both change scores and cut-offs likely to indicate dementia. A specificity of 73% was reported in an elderly intellectual disabilities sub-group and 75% in a Down syndrome sub-group. This was independent of pre-morbid intellectual functioning. However, it has been reported previously that the DLD has poor inter-rater reliability (Evenhuis, 1996). Another key difficulty with the tool in clinical practice is accurately determining the level of intellectual disability of the patient. This is likely a contributory factor to its lack of reliability between raters. Despite the earlier assertions within the manual that the tool is most sensitive when used longitudinally, suggestions have been made previously regarding modifying cut-offs to ameliorate relatively low longitudinal sensitivity from 60% to 82% (Prasher, 1997).

In line with Zeilinger et al.'s (2013) recommendation that all dementia screening tools be further evaluated, this evaluated two tools recommended in the most recent BPS (2009) guidelines 'Dementia and People with Intellectual Disabilities'. Specifically, this exploratory study intended to identify whether the tools accurately differentiate between two groups; those who develop dementia and those who do not. It is also intended to identify any pattern of age related change between those who develop dementia and those who do not.

## **1.2 Local Procedure**

The data to be examined within the study was collected at a Down Syndrome Health Screening Clinic. Data is collected annually until such time as the patient receives a diagnosis of dementia. Assessment involves a comprehensive, multi-disciplinary process which also involves screening for any physical health conditions that may give rise to symptoms similar to those observed in dementia (e.g. hypothyroidism). A multi-disciplinary consensus is reached with

regard to whether the patient requires further diagnostic assessment.

The following exploratory study aimed to investigate whether differences could be found in patterns of responses in adults with Down Syndrome who develop dementia and those who do not and the predictive accuracy of two dementia screening measures. These were the Adaptive Behaviour Dementia Questionnaire (ABDQ; Prasher et al, 2004) and the Dementia Questionnaire for People with a Learning Disability (DLD; Evenhuis et al, 2007). The research questions were; 1) Is there a particular sub-scale of the DLD that is more predictive of dementia than others? 2) Is the ABDQ or the DLD better able to distinguish between the 'dementia' and 'no dementia' group 3) Is there an observable pattern of responding which distinguished between normal and abnormal ageing in this population.

## **2. Method**

### **2.1 Participants**

The participants were patients who had attended the Down Syndrome Health Screening Clinics with their carer or family member acting as informant to complete the ABDQ or the DLD. All participants had an intellectual disability and Down syndrome. An attempt was made to obtain IQ data, but this was unavailable for the majority of the data set and was therefore not included in the analysis. Education level and living arrangements of participants was also unavailable. The primary data set consisted of 64 participants selected from a possible total of approximately 130 participants who had attended the Down Syndrome Health Screening Clinic. Participant files used were those that were available i.e. identified by the database administrators and sent to be reviewed by the researcher. The remaining

participants' data was not collected due to the substantial time and resource that this would have required.

As the primary data set consisted of retrospective clinical data, it was not possible for participants to be age-matched in the way that might have been possible with a prospective study. Therefore a secondary data set, specifically selected from within the primary data set consisted of an age-matched group of 22 participants. This controlled for age as a confounding variable i.e. subsequent analysis would identify any differences in results which could have been due to a non age matched sample in the primary data set.

Half of the participants (n=32) from within the full data set had previously been diagnosed with dementia, forming the 'dementia' group to be compared against the 'no dementia' group. Diagnosis for these individuals followed the best practice guideline Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia (BPS, 2009).

Essentially, diagnosis was made following a multi-disciplinary team assessment, collating information from various professions including psychology, psychiatry, nursing occupational therapy, and speech and language therapy. The multi-disciplinary teams which made a diagnosis in these cases follow this 'gold standard' guidance which also states that 'the clinical or other qualified psychologist and psychiatrist will be the key disciplines involved in



reviewing the outcome of multidisciplinary assessment and then arriving at a diagnosis, with support from the multidisciplinary team' (BPS, 2009).

## **2.2 Data Collection**

Psychology records for each patient attending the DSHSC between 2005 and 2015 were reviewed retrospectively and relevant data retrieved. No patient contact was required. All available pre-existing total scores on the Adaptive Behaviour Dementia Questionnaire (ABDQ) and total and sub-scores on the Dementia Questionnaire for people with Learning Disabilities (DLD) were collated. The data recording sheet included sections for demographic data such as gender and age as well raw scores and other relevant information. This section also included a participant number. This unique number was linked to patient names to ensure the data could be traced back to patient files if required. Names of patients, required as the key to participant numbers were kept separately and securely in accordance with data protection and Caldicott guardian guidelines. The data had been collected previously as part of routine clinical practice. Caldicott Guardian approval to access the data was sought and granted (see Appendix 4). The project was registered with the local NHS Research and Development Service and NHS Clinical Governance team as required by local research protocol and guidelines.

## **2.3 Data Analysis Strategy**

Analyses were conducted using IBM SPSS Statistics (2015). Though longitudinal data across approximately twelve time points was collected, the three data points from baseline(BL), time-point 1(TP1) and time-point (TP2) two were selected for analysis as this ensured that 90.6% of participants were included (i.e. 90.6% of the participants in the data set has

completed the measures across BL, TP1 and TP2). The period of time between BL to TP1 and TP1 to TP2 was approximately 1 year, therefore the data analysed was across a two year period. Mean scores at BL, TP1 and TP2 were calculated for ABDQ total score, DLD total score, Sum of Cognitive Scores (SCS), Sum of Social Scores (SOS) and the individual component parts of these subscales; Short-term memory (STM), Long-term memory (LTM), Spatial and temporal orientation (STO), Speech (SP), Practical Skills (PS), Mood (M), Activity and Interest (AI), Behavioural Disturbance (BD). Analysis was conducted across the primary data-set (n=64) and a secondary age matched data-set (n=22). A repeated measures MANOVA was conducted to test the differences between the two groups; those who were later diagnosed with dementia and those who were not over time. Finally, a series of receiver operating characteristics (ROC) curve analyses were conducted to determine the accuracy of the ABDQ and the DLD in predicting the onset of dementia in the population sampled.

### **3. Results**

The use of three time points across a two year period ensured that 90.6% of the participants within the full data-set and 100% of the participants within the age-matched data set were included within the analysis (see Table 1). At TP3, only 48 of the 64 participants in the full data set had useable data (75%) and this was therefore chosen as the cut-off. In the age matched data set 100% of the participants had useable data at TP2.

The primary data set consisted of 64 participants; 32 participants within both the ‘dementia’ and ‘no dementia’ groups. The age range within this group was 42-74 years with a mean age of 57.25. Of the 64 participants, 30 were male with a mean age of 59 years and 34 were female with a mean age of 56 years. The secondary data set consisted of an age-matched group of 22 participants; 11 participants within both the ‘dementia’ and ‘no dementia’ groups. The age range within this group was 47-64 years with a mean age of 55.18. Of the 22 participants, 7 were male with a mean age of 54.57 and 15 were female with a mean age of 55.47.

Table 1. Percentage of participant data by time-point

Time-point	Full data set (n=64)		Age matched data-set (n=22)	
	Number of participants (n)	Percentage of all participants (%)	Number of participants (n)	Percentage of all participants (%)
Baseline (BL)	64	100%	22	100%
Time-point 1(TP1)	62	96.9%	22	100%
Time- point 2(TP2)	58	90.6%	22	100%
Time-point 3(TP3)	48	75%	20	90.9%

### 3.1 ABDQ Main Results

As shown in Table 2, total ABDQ scores over time show that the tool accurately differentiates between those who receive a diagnosis of dementia and those who do not. As hypothesised,

overall scores in both the full and age-matched data sets for the ‘dementia’ group are higher at all three time-points. In the full data set at baseline, the mean total score in the ‘no dementia’ group was 37.6 compared to the ‘dementia’ group mean of 44.8. There is then an increase in the mean total score in the ‘dementia’ group from 44.8 to 52.1, an increase of approximately 7 points. In comparison the mean total score in the ‘no dementia’ group increases from 37.6 to 40.7, an increase of only 3 points. Figures 1 shows the scores for the ‘dementia’ and ‘no dementia’ group in the full data set over time.

Table 2. Mean total scores ABDQ by group

	Full data set (n=64)		Age matched data set (n=22)	
Time-point	No Dementia	Dementia	No Dementia	Dementia
Baseline (BL)	37.6	44.8	42.7	45.6
Time-point 1(TP1)	40.7	52.1	43.8	55.3
Time-point 2(TP2)	42.2	53.4	45.2	65.3

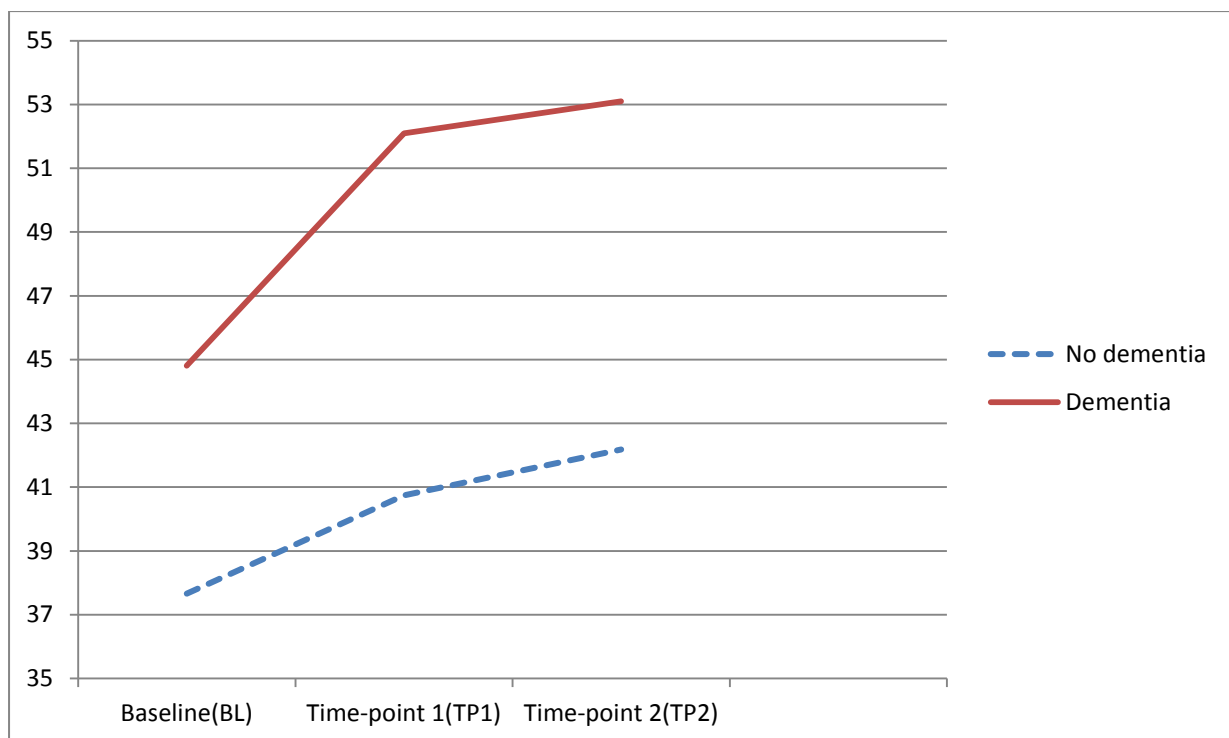


Figure 1. Mean ABDQ total scores over time (full data set)

In the age-matched data set at baseline, the mean total score in the ‘no dementia’ group was 42.7 compared to the ‘dementia’ group mean of 45.6. There is then an increase in the mean total score in the ‘dementia’ group from 45.6 to 65.3, an increase of approximately 20 points. In comparison the mean total score in the ‘no dementia’ group increases from 42.7 to 45.2, an increase of only 3 points approximately. The age-matched data set demonstrates a more pronounced pattern of increasing scores over time (see Figure 2).

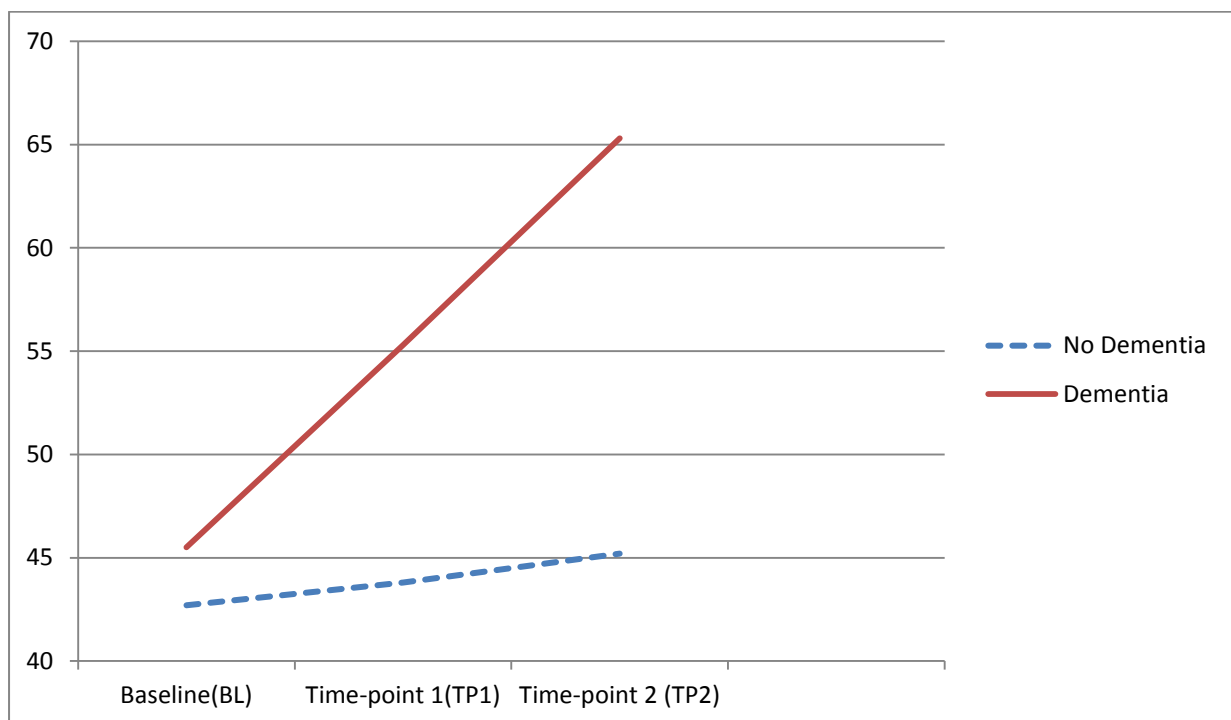


Figure 2. Mean ABDQ total scores over time (age-matched data set)

### 3.2 DLD Main Results

Total DLD scores over time also demonstrate that the tool differentiates between those who later go on to receive a diagnosis of dementia and those who do not (Table 3).

Table 3. Mean total score DLD by group

	Full data set (n=64)		Age matched data set (n=22)	
Time-point	No Dementia	Dementia	No Dementia	Dementia
Baseline (BL)	31.3	32.2	29.4	29.5
Time-point 1(TP1)	33.5	37.0	27.2	36.2
Time-point 2(TP2)	34.8	43.9	28.5	47.6

As hypothesised, overall scores in both the full data set and the age matched data set in ‘dementia’ group were higher at all three time-points. At baseline the mean total score in the ‘no dementia’ group in the full data set was 31.3. This was relatively similar in the ‘dementia’ group where the baseline mean was 32.2. Overall across the three time-points, there is a 3 point increase in the mean total score in the ‘no dementia’ group from 31.3 to 34.8, compared to an 11 point increase in the ‘no dementia’ group the mean total score increases from 32.2 to 43.9.

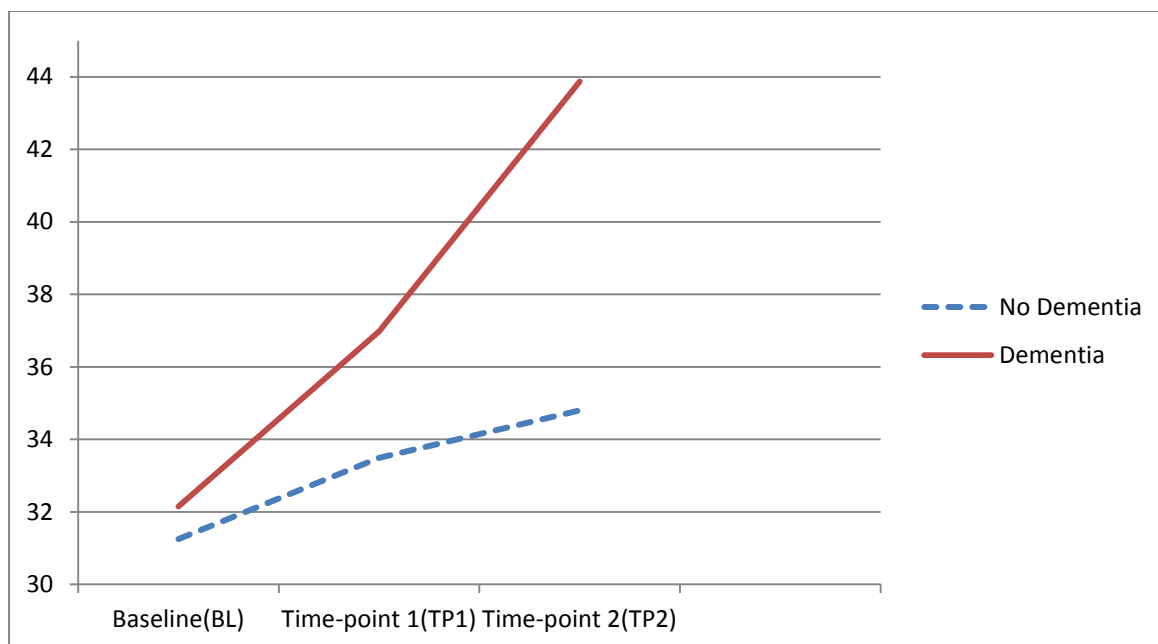


Figure 3. Mean DLD total scores over time (full data set)

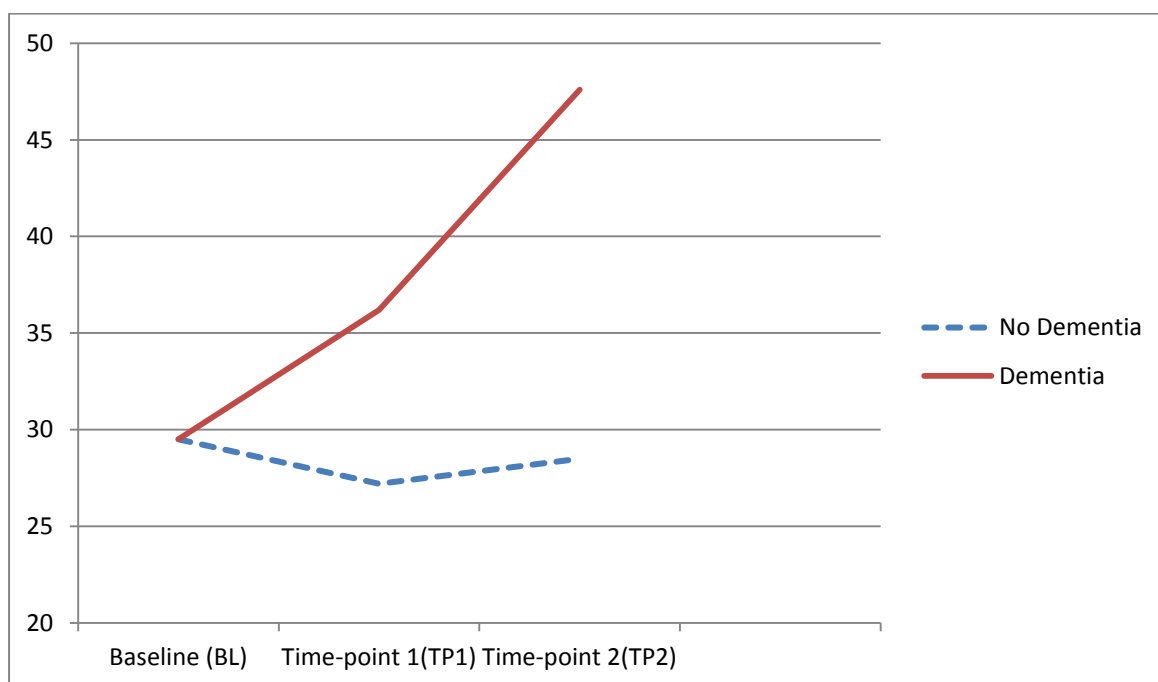


Figure 4. Mean DLD total scores over time (age-matched data set)

In the age-matched data set at baseline, the mean total score in the 'no dementia' and 'dementia'

group was almost the same figure at 29.4 and 29.5 respectively. In the ‘dementia’ group the scores over time fluctuate from 29.4 at baseline, to 27.2 at TP1 and 28.5 at TP2. In comparison the mean total score in the ‘no dementia’ group increases from 29.5 to 47.6, an increase of approximately 18 points. It would appear that the age-matched data set demonstrates a more pronounced pattern of increasing scores over time.

### 3.3 Sum of Cognitive Main Results

As shown in Table 4, total SCS scores over time indicate that the tool differentiates between those who receive a diagnosis of dementia and those who do not. In the full data set at baseline, the mean total score in the ‘no dementia’ group was 17.7 compared to the ‘dementia’ group mean of 18.4. There is then an increase in the mean total score in the ‘dementia’ group from 18.4 to 23.4, an increase of 6 points. In comparison the mean total score in the ‘no dementia’ group increases from 17.7 to 19.2, an increase of under 2 points. Figure 3. shows the scores for the ‘dementia’ and ‘no dementia’ group in the full data set over time. In the age-matched data set at baseline, the mean total score in the ‘no dementia’ group was 15.7 compared to the ‘dementia’ group mean of 16.4. There is then an increase in the mean total score in the ‘dementia’ group from 16.4 to 24.8, an increase of over 8 points. In comparison, the mean total score in the ‘no dementia’ group decreases from 15.7 at BL to 15.2 at TP2, an overall decrease of 0.5 points (3.2%).

Table 4. Mean total score Sum of Cognitive Scores (SCS) by group

	Full data set (n=64)		Age matched data set (n=22)	
Time-point	No Dementia	Dementia	No Dementia	Dementia



Baseline (BL)	17.7	18.4	15.7	16.4
Time-point 1(TP1)	18.2	20.4	15.0	19.6
Time-point 2(TP2)	19.2	23.4	15.2	24.8

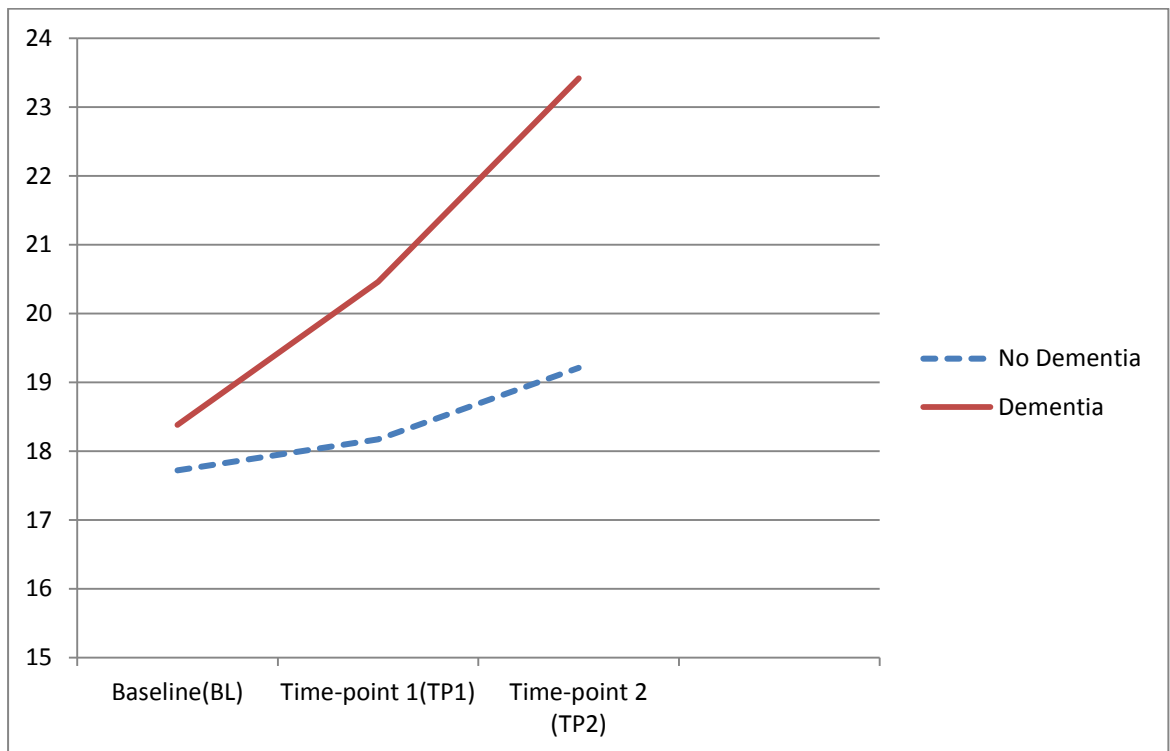


Figure 5. Mean Sum of Cognitive Scores (SCS) over time(full data set)

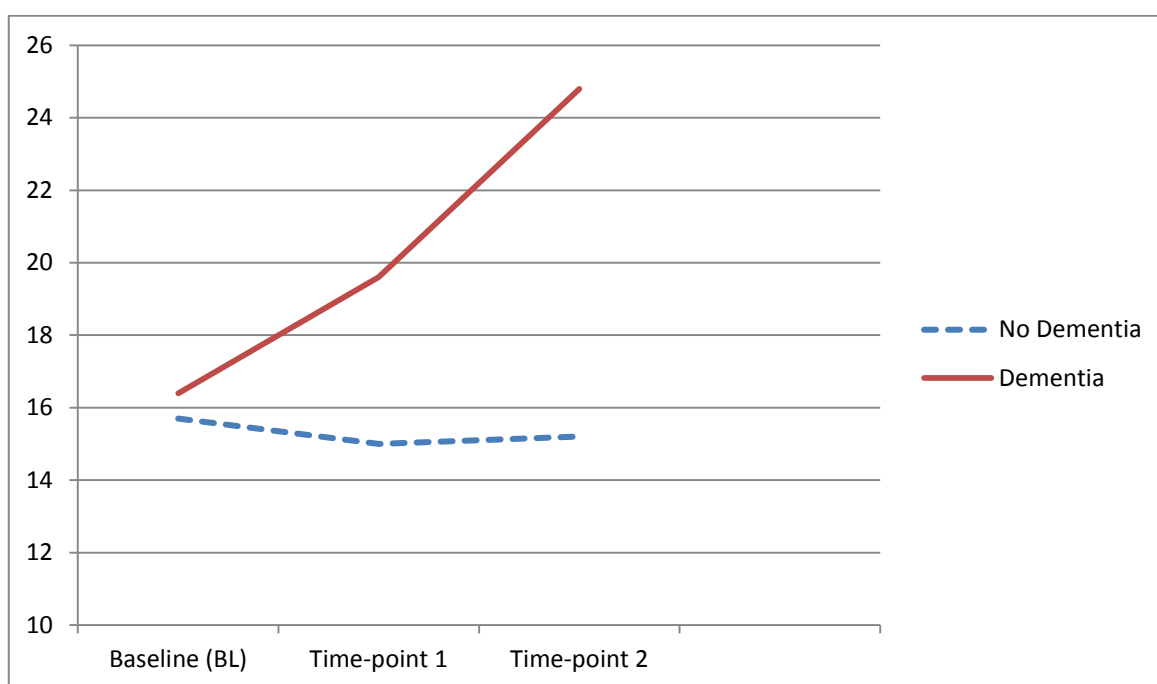


Figure 6. Mean Sum of Cognitive Scores (SCS) over time (age-matched data set)

### 3.4 Sum of Social Main Results

As shown in Table 4, total SOS scores over time suggest that the tool differentiates between those who receive a diagnosis of dementia and those who do not. In the full data set at baseline, the mean total score in the ‘no dementia’ group was 13.5 compared to the ‘dementia’ group mean of 13.7. There is then an increase in the mean total score in the ‘dementia’ group from 13.7 to 20.5, an increase of just under 7 points. In comparison the mean total score in the ‘no dementia’ group increases from 13.5 to 15.6, an increase of just over 2 points. Figure 5. shows the scores for the ‘dementia’ and ‘no dementia’ group in the full data set over time. In the age-matched data set at baseline, the mean total score in the ‘no dementia’ group was 13.7

compared to the ‘dementia’ group mean of 13.2. There is then an increase in the mean total score in the ‘dementia’ group from 13.2 to 23.3, an increase of over 10 points. In comparison, the mean total score in the ‘no dementia’ group increases from 13.7 at BL to 13.4 at TP2, an overall decrease of 0.3 points (0.3%).

Table 5. Mean total score of Sum of Social Scores (SOS) by group

	Full data set (n=64)		Age matched data set (n=22)	
Time-point	No Dementia	Dementia	No Dementia	Dementia
Baseline (BL)	13.5	13.7	13.7	13.2
Time-point 1(TP1)	15.3	16.5	12.2	16.7
Time-point 2(TP2)	15.6	20.5	13.4	23.3

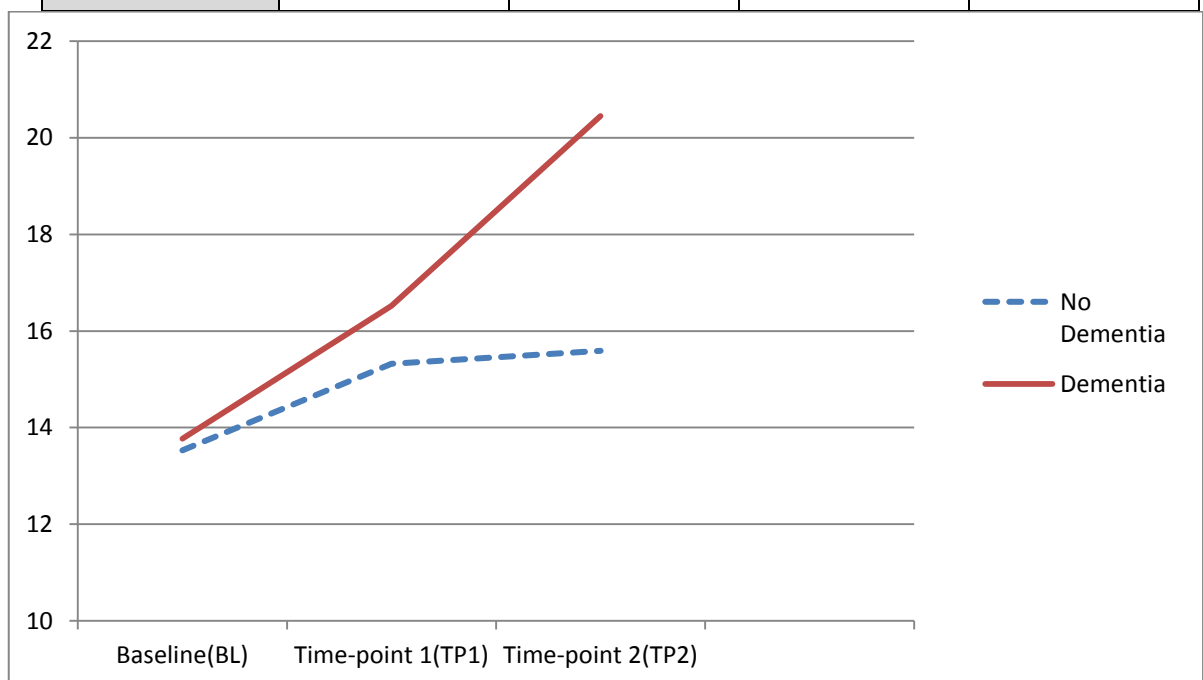


Figure 7. Mean Sum of Social Scores (SOS) over time (age-matched data set).

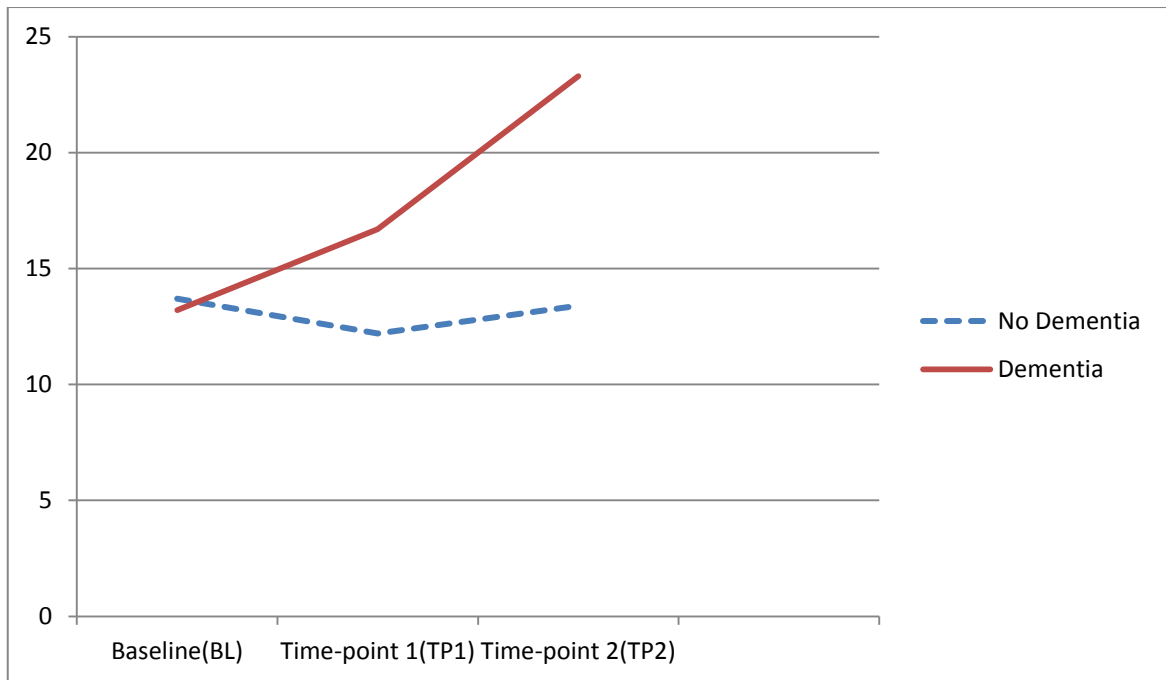


Figure 8. Mean Sum of Social Scores (SOS) over time (age-matched data set)

Table 6. summarises the main results across both data the full and age-matched sets with regard to the number of points (percentage) change from BL to TP2. Of the individual DLD domains the highest change was observed within ‘practical skills’. This was 42% for the full data set and 62.9% for the age-matched data set.

	Full data set		Age-matched data set	
	No Dementia	Dementia	No Dementia	Dementia
ABDQ	↑4.6 (11.4%)	↑8.6(16.2%)	↑2.5(5.6%)	↑19.7(30%)
DLD	↑3.5(10.1%)	↑11.6(26%)	↓0.9(3.1%)	↑18.1(38.1%)
SCS	↑1.5(7.9%)	↑5.0(21.4%)	↓0.5(3.2%)	↑8.4(33.9%)
SOS	↑2.1(13.5%)	↑6.8(33.2%)	↓0.3(2.2%)	↑10.1(43.4%)
STM	↑0.9(17.4%)	↑2.4(32.5%)	↑0.9(18%)	↑3.9(47%)
LTM	↑0.6(8.2%)	↑1.1(13.5%)	↓0.3(5.3%)	↑3.4(37.8%)

STO	↑0.1(1.5%)	↑1.5(19.3%)	↓1.3(21.7%)	↑1.0(13.6%)
SPEECH	↑0.2(8.7%)	↑1.0(35.8%)	↑0.4(21.1%)	↑1.6(43.3%)
PRACTICAL SKILLS	↑0.8(30.8%)	↑1.3(42%)	↑0.4(15.4%)	↑2.2(62.9%)
MOOD	↓0.1(2.6%)	↑1.9(32.3%)	↓0.6(16.7%)	↑2.2(33.9%)
ACTIVITY AND INTEREST	↑1.0(27.8%)	↑1.4(33.4%)	↑0.2(5.8%)	↑2.7(53%)
BEHAVIOURAL DISTURBANCE	0(0%)	↑1.1(25%)	↓0.8(24.3)	↑1.4(30.5%)

Table 6. Points(Percentage) change over time by group (baseline to TP2)

### 3.5 Repeated Measures MANOVA

A repeated measures MANOVA was conducted, for both the full and age-matched data sets, to test the interaction effects on dementia screening scores over time by group. For the full data set, the results showed that there was no significant differences between ‘dementia’ and ‘no dementia’ groups on the ABDQ and DLD scores together over time, Pillai’s Trace = .041,  $F(2, 55) = 1.161$ ,  $p < 0.321$ . No significant differences was also observed in dementia screening scores over time by group in the age-matched data set, Pillai’s Trace = 0.003,  $F(2, 19) = 0.27$ ,  $p < 0.973$ . Due to the results being non-significant post hoc testing was not indicated.

### 3.6 Receiver Operating Characteristics (ROC) Curve Analysis

A series of receiver operating characteristics (ROC) curve analyses were conducted across all three time points for both the full and age-matched data set. With regard to the ABDQ, analysis of the full data set yielded an area under the curve for the ranging between 0.720 at time point 1 to 0.709 at time point 3. This would suggest that the test can be considered of ‘fair’ quality when assessing for the presence of dementia in this group. In the age matched group the area under the curve for the ABDQ ranged from 0.628 at time point 1 to 0.748 at time point 3. This would suggest that the test can be considered as ‘poor – fair’ quality. With regard to the DLD, analysis of the full data set yielded an area under the curve for the ranging between 0.524 at time point 1 to 0.633 at time point 3. This would suggest that the test can be considered of ‘worthless to poor’ quality when assessing for the presence of dementia in the population sampled. In the age matched group the area under the curve for the DLD ranged from 0.579 at time point 1 to 0.793 at time point 3. This would suggest that the test can be considered as ‘poor to fair’ quality. For further information on ROC analysis and the rating cut-offs for the area under the ROC curve, please refer to Hanley and McNeil (1982).

	Full data set			Age-matched data set		
	Are under the curve (AUC) at Time Point	Area Under the curve (AUC) at Time Point	Area Under the curve (AUC) at Time Point	Are under the curve (AUC) at Time Point	Area Under the curve (AUC) at Time Point	Area Under the curve (AUC) at Time Point

	1	2	3	1	2	3
ABDQ	0.720	0.710	0.709	0.628	0.719	0.748
DLD	0.524	0.572	0.633	0.579	0.698	0.793

Table 7. Area under the curve values for ABDQ and DLD in full and age-matched data sets

In summary, the results as shown in figures 1- 8 suggest that both the ABDQ and DLD scores over time differentiated between those who develop dementia and those who not. It was also clear that there was a more pronounced effect in the age-matched data set. Despite this the MANOVA did not reach statistical significance, suggesting that no such pattern existed. ROC analysis yielded further evidence that the tools were not particularly reliable or sensitive in detecting dementia in the population sampled.

#### 4. Discussion

As hypothesised, the mean total ABDQ, DLD, SCS, SOS and individual DLD domain scores, all differentiate between the ‘dementia’ and ‘no dementia’ groups with total scores being higher in the ‘dementia’ group in both the full and age-matched data sets. Overall, the differences between groups was more pronounced in the age-matched data set. Despite the clear pattern of elevated scores over a two year time period in the ‘dementia’ group compared to the ‘no dementia’ group, no significant interaction effects were found on dementia screening scores over time by group. This might in part be due to the small sample

size of both the full and age-matched data set. Another possibility is that the tools are not sensitive enough in identifying the changes associated with the onset of dementia in people with intellectual disabilities.

#### **4. 1 Clinical Relevance**

The findings presented here would suggest that both the ABDQ and the DLD may be useful tools to aid clinicians in differentiating between normal and abnormal ageing in this population. Furthermore, it would seem that the tools are able to highlight even at this early stage i.e. the period from baseline to TP2, a period of two years, an observable difference between the ‘dementia’ and ‘no dementia’ groups. This might suggest that prolonged assessment over several years is not necessarily the most cost effective or efficient way to monitor or assess for dementia in intellectual disability. Previously Jones et al (2009) had highlighted how this model of assessment could be considered resource intensive. However, this assumption would have to be explored in greater depth before any meaningful conclusions could be drawn and the resultant change in practice. Given the nature of dementia assessment being longitudinal, it could be argued that the process may become arduous to adhere to for the patient and their carer, resulting in ‘drop outs’ from assessment. Jones et al (2013) acknowledged that often additional support may be required including transport, providing information, remembering appointments and following through with recommendations made and that this role often falls to inexperienced health and social care



staff. It may also be possible that the ‘dementia’ and ‘no dementia’ groups within this population are actually fundamentally different in some key domain. Exploratory factor analysis of the individual items and domains within dementia screening tools might be one way to begin to explore these differences further. The ultimate goal of this would be to aid the early identification of dementia within people with intellectual disability.

The ROC analyses would suggest that neither the ABDQ nor the DLD were particularly reliable in predicting who was developing dementia in the population sampled, with ratings only reaching ‘fair’ quality. The increase in the area under the curve value over time may in fact reflect dementia symptoms becoming more obvious to the raters of the tools, rather than the tools becoming more accurate in predicting dementia.

## **4.2 Limitations of Current Research**

One key limitation of the research presented here is the use of retrospective, longitudinal clinical data. While longitudinal data is highly desirable in clinical research, this has in some cases led to inconsistencies in the data collected, as local practice has shifted over time. For example, information relating to level of learning disability could not be controlled for as many participants had never been formally assessed. In addition, of those who had been assessed, the tools used to complete a cognitive assessment varied and therefore could not be reliably used for comparison. Information with regard to where participants were living was

also unavailable and may have changed over the assessment period. In the 2001 Department of Health Report, Valuing People it was estimated that almost two thirds of people with learning disabilities live with their families, 37% in communal housing (rising to 70% of those aged 55 or over). However a further commentary on dementia screening in a learning disability service noted a differing compliment where 40% of the adults with Down Syndrome were living with their families, 53% in residential homes for people with learning disabilities, 8% in supported living and 1 person living in a care home (McBrien, 2005). In a prospective study it may be useful to track this information to identify if dementia is identified earlier in a particular setting.

Furthermore, given the data was collected clinically over a substantial time period, there was inevitably individual missing items. In these instances, missing data could not be followed up and rectified due to the retrospective design. A further limitation of the study is the small sample size which may have contributed to the non-significant interaction effects found.

Despite these limitations the study has utilised data directly from a clinical population. This is not only potentially highly informative, but conclusions drawn from such research have the potential to alter and define clinical practice into the future. A further limitation of the study was the difficulties in age matching the data. In the full data set this was not possible due to the retrospective design. However, having collated the data for the full data set (n=64) and reviewing ages, an age matched data set was selected for analysis. Inevitably this meant a

much smaller sample of people (n=22). Ideally, in a prospective research design, the sample size would have been larger than either the full or the age matched comparison data set. This would allow for further exploratory factor analysis. This could not be performed within this study as power would have been insufficient.

#### **4. 3 Recommendations for Future Research**

Continued exploratory evaluation of available data is a clearly necessary to advance the current knowledge around dementia screening in intellectual disability. It is recommended that this be conducted at both local and national levels. This would highlight possible variations in the data across different areas and populations but also demonstrate areas of consistency in the research. If the research had been a prospective study it would have been prudent to ensure that the number of participants included allowed sufficient power to conduct further exploratory factor analysis. This may have yielded further interesting results with regard to individual items and domains within the DLD and their ability to accurately identify possible dementia in this population. It is also recommended that identifying the level of learning disability in a consistent way would allow for further analysis with respect to the patterns of ageing between mild-moderate and severe-profound intellectual disability groups to be established.

One of the challenges in conducting this research was the process of local data collection

itself. As participants were from three separate localities, data was stored in separate locations with different operating systems and databases in place for its management. This posed some challenges in both identifying the data in the first place, selecting the cases for collation and then in subsequently accessing the paper files themselves which were either stored in a further location or were currently open to one of a number of clinicians. In addition to this, the sheer volume of data to be collected was vast, given the annual attendance of participants across, in some cases, 12 years.

## **5. Conclusions**

In conclusion, the study has demonstrated that visual inspection of ABDQ and the DLD scores over time showed a pattern of increasing scores in those who develop dementia as compared to those who do not. However, given the non-significant results yielded by MANOVA and the low area under the curve values identified by ROC analysis, further analysis would be indicated before making any definitive conclusions. This might seek to incorporate an in-depth exploration of the individual component items of the tools, allowing us to isolate particular items, using exploratory factor analysis, which could be more

predictive of a later diagnosis of dementia. Prospective collection of data would also allow for greater ability to control for confounding variables. Increasing the sample size may also demonstrate a greater effect size. These conclusions are supported by Starkey et al (2014) who suggest it is unlikely that the subtle early signs of dementia in Down Syndrome will be picked up by this type of screening. They also point toward further research to evaluate whether current screening frequency is actually allowing us to identify dementia any earlier or not.

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## APPENDICES

Appendix 1: Assessments used at DSHSC (reproduced from Jones et al, 2009)

Appendix 2: JARID Author Guidelines

Appendix 3: Data Recording Sheets

Appendix 4: Caldicott /Ethics Forms

# APPENDIX 1: Assessments used at Down Syndrome Health Screening Clinic

Station	Professional	Assessment Carried out
A	Medic	Blood Sample taken in relation to thyroid function
1	Nursing	Health Check (including Mental Health)  Urine Sample taken to check for thyroid function and infection.  Blood pressure and pulse assessment, respirations  Hearing check
2	Podiatrist	OK Health Check  Basic biomechanical check  Vascular assessment  Footwear check  Mobility check
	Dietician	OK Health Check

		Weight, height and BMI measured
	Physiotherapist	OK Health Check  Physical ability screen – includes posture, joint range of movement & gait assessment  Current level of exercise participation recorded
3	Clinical Psychologist	Dementia Screening Assessment – The Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities (CAMSEX-DS); Dementia Questionnaire for people with a Learning Disability (DLD); Adaptive Behaviour Dementia Questionnaire (ABDQ)

Table 1. Assessments Used by Profession (Reproduced from Jones et al, 2013)

# Journal of Applied Research in Intellectual Disabilities

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Data Collection Form



Participant Number								
D.O.B / Current Age								
Gender (circle as appropriate)	M				F			
Clinical Diagnosis								
Locality Clinic								
Baseline (date)								
No. of Follow ups								
ABDQ Total Scores (at baseline, time-point 2 etc.)	BL	TP 1	TP 2	TP 3	TP 4	TP 5	TP 6	TP 7
DLD Total Scores (at baseline, time-point 1 etc.)	BL	TP 1	TP 2	TP 3	TP4	TP 5	TP 6	TP 7
SCS (Sum of Cognitive Scores)								
SOS (Sum of Social Scores)								
Dementia Diagnosis Yes/No/Maybe/Don't Know								



Data Collection Form



<p>Dementia Diagnosis Information</p>	
<p>Further Relevant Information</p>	

Data Collection Form - ABDQ



Participant No:

Date of Data Collection:

ABDQ Responses														
Coded: Better (0) Same as Normal (1) Worse/less than normal (2) Much worse/less than normal (3)														
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Sum of Scaled Scores	A			B			C			D			E	
TOTAL							Dementia (yes if total $\geq 78$ )							

# Data Collection Form – DLD



Participant No:  
Date of Data Collection:

SCS =  
SOS =

Total=

DLD Responses Coded 0, 1, 2			
Question No.	0	1	2
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Data Collection Form – DLD



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Administration only:  
Date application received DPCC 28/05/14  
Expected Approval Date 24/06/14

## Appendix 6

### APPLICATION FOR CALDICOTT APPROVAL FOR USE OF PATIENT IDENTIFIABLE DATA

#### User Details

**Name:** Laura Williams  
**Position:** Specialist Psychological Practitioner  
**Organisation:** NHS Fife  
**Address:** Psychology Dept, Lynebank Hospital  
**Postcode:**  
**Tel. No.:** (01383) 565 210  
**E-mail:** laurawilliams3@nhs.net  
**Name(s) of any co-user(s):** Jill Jones - Project Supervisor

You must address the 6 Caldicott Principles when submitting this request for data

#### 1. Project/Audit title

An Investigation into the Reliability of  
Dementia Screening Tools for Patients with  
Downs Syndrome.

#### 2. Please provide additional background description of your project/audit to enable Caldicott Guardian to understand what outcome you trying to achieve.

The project will investigate whether the current  
screening tools (ABDQ & DLD) are sensitive/  
reliable.

#### 3. Supporting information

Please list and attach any other supporting information, e.g. Project proposal, ethics approval, data protocol, safe haven arrangements, correspondence.



4. Name of organisation receiving data (if not within NHS Fife)

Not applicable.

5. What patient identifiable information are you looking to use?  
(please tick where relevant)

CHI Number	
Forename	
Surname	
Initials	
Age	✓ Relevant to testing frequency.
Date of birth	
Gender	
Address	
Postcode	
Other, please specify.....	Screening Test Results

6. Please explain how the proposal meets the following Six Caldicott

**Principles.** (The Caldicott Committee Report on the Review of Patient-Identifiable Information. Department of Health, December 1997)

**Justify the purpose**

<b>Principle 1</b> Justify the purpose(s)	Every proposed use or transfer of patient-identifiable information within or from an organisation should be clearly defined and scrutinised, with continuing uses regularly reviewed, by an appropriate guardian.
--	---

The project investigates reliability of current measures used. This will allow us to identify whether current clinical practice is appropriate and resource effective i.e. do patients need to be screened so often.

**Justify the requirement to use patient-identifiable data**

<b>Principle 2</b> Don't use patient-identifiable information unless it is absolutely necessary	Patient-identifiable information items should not be included unless it is essential for the specified purpose(s) of that flow. The need for patients to be identified should be considered at each stage of satisfying the purpose(s).
--	---

I will only need access to test results and age of the patient.



**Justify the inclusion of each data field required**

<b>Principle 3</b> Use the minimum necessary patient identifiable information	Where use of patient-identifiable information is considered to be essential, the inclusion of each individual item of information should be considered and justified so that the minimum amount of identifiable information is transferred or accessible as is necessary for a given function to be carried out.
--	--

I will be using the minimum data necessary - age, test results.

**Please outline arrangements for access to information**

<b>Principle 4</b> Access to patient-identifiable information should be on a strict need-to-know basis	Only those individuals who need access to patient-identifiable information should have access to it, and they should only have access to the information items that they need to see. This may mean introducing access controls or splitting information flows where one information flow is used for several purposes.
---	---

This is data already collected for clinical purposes  
I will only access necessary information through file review. Possibility Till Jones - project supervisor may also review it.

**Please outline action taken to ensure compliance with responsibilities and obligations to respect patient confidentiality**

<b>Principle 5</b> Everyone with access to patient-identifiable information should be aware of their responsibilities	Action should be taken to ensure that those handling patient-identifiable information - both clinical and non-clinical staff - are made fully aware of their responsibilities and obligations to respect patient confidentiality.
--	---

I am fully aware of my responsibilities regarding this data and patient confidentiality. Currently working as a Specialist Psychological Practitioner.

**Please outline organisational compliance with legal requirements**

<b>Principle 6</b> Understand and comply with the law	Every use of patient-identifiable information must be lawful. Someone in each organisation handling patient information should be responsible for ensuring that the organisation complies with legal requirements.
--	--



Psychology Dept. and University of Edinburgh  
both comply with Caldicott principles.

7. Has your application been to Research Ethics  
If not, please explain why (i.e. not research)

YES/NO

Project still at earlier stage. Will clarify  
whether full ethical review is required and  
submit in due course.

Please note that any significant changes to the above arrangements must be notified  
by resubmitting an application detailing the amendments. See C9 Confidentiality  
Policy Appendix 9.

8. Who is the data custodian for the NHS Fife data?

Name: DR KATHERINE CHERRE

Job Title: HEAD OF PSYCHOLOGY SERVICE

Return Address: LYNEBANK HOSPITAL

Email Address: kcherre@nhs.net

Telephone Number: 01383 585403

Signature:  Date: 26.5.14.

Counter-signature by Line Manager

Name: ALISON ROBERTSON

Job Title: HEAD OF LD PSYCHOLOGY

Signature:  Date: 23/5/14

Please forward to:

Data Protection & Caldicott Coordinator (DPCC)  
NHS Fife  
Information Services Department  
Lynebank Hospital  
Dunfermline KY11 8JH





Counter-signature by Acute Services/Primary Care Caldicott Guardian

Name: SA Croke

Job Title: Medical Director, Ramsgate Care

Signature: SA Croke Date: 27/5/14

I authorise access to the data as noted above:

Signature: DR EDWARD COYLE Date: 19/6/14  
Caldicott Guardian for NHS Fife

Expiry Date

An expiry date of 01/05/17 has been set for this application. If your audit, project or evaluation runs over that date, you must submit a Continuation request. See C9 Confidentiality Policy Appendix 9.

ADMIN USE ONLY

Applicant's Name & Project Title <u>Williams, Laura</u> <u>Investigation into screening tools (dementia) for pts with Dementia Syndrome.</u>	
Date application received Data Protection Caldicott Coordinator (DPCC)	<u>28/5/14.</u>
Expected Approval Date 20 working days	<u>24/06/14.</u>
Date sent for approval to CG Acute (PC)	<u>28/05/14</u>
Date sent to Board CG for formal approval	
Date received by DPCC	
Date applicant informed	
20 days time scale met?	Y N



RECEIVED

17 DEC 2014

## Appendix 9

APPLICATION FOR CONTINUATION or AMENDMENT  
TO CALDICOTT APPROVAL FOR USE OF  
PATIENT IDENTIFIABLE DATAContinuation of project, evaluation or audit ☐ please tickAmendment to approved project, evaluation or audit ☒ please tick. Details of  
significant changes should be shown in red.User Details

Name: Laura Williams

Position: Specialist Psychological Practitioner

Organisation: NHS Fife

Address: Psychology Dept. Lynebank Hospital

Postcode: KY11 4UW

Tel. No.: (01383) 565 210

E-mail: laurawilliams83@nhs.net

Name(s) of any co-user(s): Jill Jones  
Project SupervisorYou must address the 6 Caldicott Principles when submitting this request for  
data

## 1. Project/Audit title

An Investigation into the Reliability of  
Dementia Screening Tools for Patients with  
Down Syndrome2. Please provide additional background description of your project/audit  
to enable Caldicott Guardian to understand what outcome you trying to  
achieve.The project will investigate whether the  
current screening tools (ABDQ & DLD) are  
sensitive / reliable.

## 3. Supporting information

Please list and attach any other supporting information, e.g. Project proposal, ethics  
approval, data protocol, safe haven arrangements, correspondence.

V1 Dec 2013

Review Date Dec 2016

**4. Name of organisation receiving data (if not within NHS Fife)**

Not applicable.

**5. What patient identifiable information are you looking to use?  
(please tick where relevant)**

CHI Number	
Forename	
Surname	
Initials	
Age	✓ Relevant to testing frequency
Date of birth	
Gender	
Address	
Postcode	
Other, please specify.....	Screening Test Results, any mood

**6. Please explain how the proposal meets the following Six Caldicott Principles.**

(The Caldicott Committee Report on the Review of Patient-Identifiable Information. Department of Health, December 1997)

**Justify the purpose**

<b>Principle 1</b> Justify the purpose(s)	Every proposed use or transfer of patient-identifiable information within or from an organisation should be clearly defined and scrutinised, with continuing uses regularly reviewed, by an appropriate guardian.
--	---

The project investigates reliability of current measures used. This will allow us to identify whether current clinical practice is appropriate and resource effective i.e. do patients need to be screened so often.

**Justify the requirement to use patient-identifiable data**

<b>Principle 2</b> Don't use patient-identifiable information unless it is absolutely necessary	Patient-identifiable information items should not be included unless it is essential for the specified purpose(s) of that flow. The need for patients to be identified should be considered at each stage of satisfying the purpose(s).
--	---



I will need access to ABDQ & DHD results and age of patient.  
In addition I will require to use mood measures/questionnaires and cognitive assessment data.

**Justify the inclusion of each data field required**

<b>Principle 3</b> Use the minimum necessary patient identifiable information	Where use of patient-identifiable information is considered to be essential, the inclusion of each individual item of information should be considered and justified so that the minimum amount of identifiable information is transferred or accessible as is necessary for a given function to be carried out.
--	--

I will be using the minimum data necessary.

**Please outline arrangements for access to information**

<b>Principle 4</b> Access to patient-identifiable information should be on a strict need-to-know basis	Only those individuals who need access to patient-identifiable information should have access to it, and they should only have access to the information items that they need to see. This may mean introducing access controls or splitting information flows where one information flow is used for several purposes.
---	---

This is data already collected for clinical purposes. I will only access necessary information through file review. Possibility Jill Jones - project supervisor may also review it.

**Please outline action taken to ensure compliance with responsibilities and obligations to respect patient confidentiality**

<b>Principle 5</b> Everyone with access to patient-identifiable information should be aware of their responsibilities	Action should be taken to ensure that those handling patient-identifiable information - both clinical and non-clinical staff - are made fully aware of their responsibilities and obligations to respect patient confidentiality.
--	---

I am fully aware of my responsibilities regarding this data and patient confidentiality. Currently working as a Specialist Psychological Practitioner bound by BPS Code of Conduct.



**Please outline organisational compliance with legal requirements**

**Principle 6**

Understand and comply with the law

Every use of patient-identifiable information must be lawful. Someone in each organisation handling patient information should be responsible for ensuring that the organisation complies with legal requirements.

Psychology Dept and University of Edinburgh both comply with Caldicott principles.

**7. Has your application been to Research Ethics**

**YES/NO**

If not, please explain why (i.e. not research)

Confirmed full ethical review not required.

**8. Who is the data custodian for the NHS Fife data?**

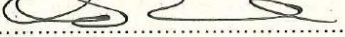
Name: DR. CATHERINE LIVERMORE

Job Title: HEAD OF PSYCHOLOGY SERVICE NHS FIFE

Return Address: Dept Psychology Lynebank Hospital Dumfries Fife KY11 4UW

Email Address: cliv@nhs.net

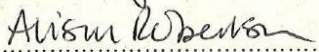
Telephone Number: 01383 585403

Signature:  Date: 8/12/14

**Counter-signature by applicant's Line Manager**

Name: ALISON ROBERTSON

Job Title: Head of CD Psychology

Signature:  Date: 8/12/14

**Please forward to:**

Data Protection & Caldicott Coordinator  
NHS Fife  
Information Services Department  
Lynebank Hospital

V1 Dec 2013

Review Date Dec 2016





Dunfermline KY11 8JH

V1 Dec 2013

Review Date Dec 2016



**Counter-signature by Acute /Primary Care Caldicott Guardian**

Name: *Dr George Ginn*

Job Title: *GP*

Signature: *George Ginn* Date: *22/12/14*

**I authorise access to the data as noted above:**

Signature: *Edward Coyle* Date: *30/12/14*  
**DR EDWARD COYLE**  
Caldicott Guardian for NHS Fife

**Expiry Date**

An expiry date of / / has been set for this continuation. If your audit, project or evaluation runs over that date, you must submit a further continuation.

**ADMIN USE ONLY**

Applicant's Name & Project Title	
Date application received Data Protection Caldicott Coordinator (DPCC)	
Expected Approval Date 20 working days	
Date sent for approval to CG Acute/PC	
Date sent to Board CG for formal approval	
Date received by DPCC	
Date applicant informed	
20 days time scale met?	Y N

Tayside medical Science Centre  
Residency Block Level 3  
George Pirie Way  
Ninewells Hospital and Medical School  
Dundee DD1 9SY

Laura Williams  
Specialist Psychological Practitioner  
Psychology Dept.  
Lynebank Hospital  
Halbeath Road,  
Dunfermline  
Fife  
KY11 4UW

Date: 13/11/2014  
Your Ref:  
Our Ref: CYA/AG/14/GA/107  
Enquiries to: Mrs Caroline Ackland  
Direct Line: 01382 383839  
Email: [Caroline.ackland@nhs.net](mailto:Caroline.ackland@nhs.net)

Dear Laura,

**Project Title: An Investigation of Dementia Screening Tools in Patients with Downs Syndrome**

You have sought advice from the East of Scotland Research Ethics Service on the above project. This has been considered by the Scientific Officer and you are advised that, based on the submitted documentation (email correspondence and table below), it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees (A Harmonised Edition).

Document	Version	Date
Thesis Proposal Form	Not specified	October 2014
Information proforma	Not specified	August 2014
Information proforma ABDQ[1]	Not specified	Not specified
Information proforma DLD	Not specified	Not specified
Approved Caldicott application form	Version 6	29/05/2014 & 14/07/2014
Email	Not specified	31/10/2014

The advice is based on the following:

- *The project is limited to using data obtained as part of usual care, but note the requirement for Caldicott Guardian approval for the use or transfer of person-identifiable information within or from an organisation*

**If the project is considered to be research you may require ethical approval as outlined in The Research Governance Framework for Health and Community Care. You may wish to contact your employer or professional body to arrange this.**

**For projects that are not research and will be conducted within the NHS you should contact the relevant local Quality Improvement Team(s) who will inform you of the relevant governance procedures required before the project commences.**

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that NHS ethical





approval is not required. However, if you, your sponsor/funder or any NHS organisation feels that the project requires ethical review by an NHS REC, please write setting out your reasons and we will be pleased to consider further. You should retain a copy of this letter with your project file as evidence that you have sought advice from the East Scotland Research Ethics Service.

Yours sincerely,



**Caroline Ackland**  
**Scientific Officer & Manager**  
**East of Scotland Research Ethics Service**

Copy to: Aileen Yell, Research Governance Officer NHS Fife



